



**Carers Information and Consultation Strategy 2012 – 2015  
'Partners in Care'**

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<b>Documents to read alongside this Strategy</b>	Carers Strategies (Wales) Measure 2010 Cardiff Carers Strategy 2010 - 2014 Cardiff Young Carers Strategy 2011 - 2015 Vale of Glamorgan Carers Strategy 2008 - 2011
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# Carers Information and Consultation Strategy 2012-2015

“Partners in Care”

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## 1. Foreword

Carers play an extremely important role in looking after and supporting people in the community. Sometimes they say that they do not receive timely, useful information to help them undertake this role and that they are not involved or consulted when decisions are made about the people they care for. The Welsh Government has recognised this and on 1<sup>st</sup> January 2012 regulations and guidance came into force to address this across Wales. For a number of years social services have had a legal requirement to identify and support carers. Now, through the Carers Strategies (Wales) Measure 2010, Welsh Government has also placed a legislative duty on the NHS in relation to services for carers in Wales.

Cardiff and Vale University Health Board (UHB), Cardiff Council and the Vale of Glamorgan Council have worked together to listen to carers views and have developed this strategy in partnership with the third sector and carers.

The Strategy builds upon the work already completed over the years by both local authorities in identifying the needs of carers, through carer events, assessments, workshops and conferences. It complements three key documents:

- Cardiff Carers Strategy 2010 - 2014
- Cardiff Young Carers Strategy 2011 - 2015
- Vale of Glamorgan Carers Strategy 2008 - 2011

The development of this strategy has provided a focus for all three statutory organisations within the boundaries of Cardiff and the Vale of Glamorgan to work together strategically in order to support carers. This joint working approach will ensure that all carers are identified as early as possible and receive the support, information and involvement that they need in a more timely, seamless and cohesive way.

Our overarching aim is to improve the provision of the support and information that carers need to help them in their role and to make sure that they are involved in decisions about the person they care for.

*Adam Cairns, Chief Executive, Cardiff and Vale University Health Board*  
*Nick Jarman, Corporate Director (People), Cardiff Council*  
*Phil Evans, Director of Social Services, Vale of Glamorgan Council*

## 2. Executive Summary

A carer is someone of any age who looks after a relative, friend or neighbour who is unable to manage without help because they are elderly, disabled by physical or mental ill health, learning disability, drug or alcohol problem or have a long-term illness. The care they provide is unpaid.

In January 2012, the Carers Strategies (Wales) Measure 2010 (the Measure) came into force in Wales.

The Carers Strategies (Wales) Regulations 2011 made under the above Measure place a duty on Local Health Boards to lead on preparing, publishing and implementing an Information and Consultation Strategy for Carers (the "Strategy"). Cardiff and Vale University Health Board are the lead organisation, and have worked in collaboration with Cardiff and the Vale of Glamorgan Councils, carers and the voluntary/third sector to develop the Strategy.

A working group has met monthly to develop the strategy. It has involved carers as well as staff from a number of organisations, including the Health Board, the Local Authorities, third sector organisations such as the Cardiff and Vale Carers Centre and the Cardiff and Vale Community Health Council. Briefing papers from each meeting were also distributed through the local County Voluntary Councils, Cardiff Third Sector Council (C3SC) and Vale Council for Voluntary Services (VCVS) to all organisations on their databases. These briefings encouraged organisations to participate in the development of the strategy and feedback has been received through this route. Members of the working group have also met with individual carers and carers groups to discuss the contents of the Strategy.

This Strategy will sit alongside and complement the Carers Strategies developed by both local authorities and the actions being undertaken by the Health Board to improve its support for carers.

The Strategy will:

- Set out how health services will identify carers as early as possible
- Set out how information will be provided to carers that will assist them in carrying out their caring role and
- Set out how carers will be consulted and involved in decisions affecting them and those they care for, and how consent issues affect consultation.

It will demonstrate a commitment to ensuring that:

- Carers are valued as partners in care
- Carers are never taken for granted
- Carers are consulted with in a timely fashion, and their knowledge of the cared for person is treated with respect
- Carers are made aware of their rights to a needs assessment
- Assistance is provided to help carers understand decisions if needed

- Consultation occurs with carers at regular intervals and includes consideration of support needed at short notice
- Due regard is taken of carers age, including child and young adult carers, and any disability and cultural needs
- Carers are made aware of support available from voluntary organisations
- Staff are trained to be aware of carers needs and rights
- The needs of carers are considered when their caring role ends
- Support is provided to improve and/or maintain carers' health and wellbeing

Five linked programmes have been developed to deliver the strategy

- A partnership framework to ensure that the Health Board, Local Councils and the third sector work together to support carers
- An awareness raising framework, to ensure that everyone who needs to be is "carer aware"
- An education and training framework, to ensure that the training needs of healthcare staff and carers are identified and met
- Carer pathways, to identify the information and support health services can provide to people throughout their time as a carer
- An information framework, to ensure that all carers are provided with appropriate information at all stages of their caring pathway

The Welsh Government will expect reports on a number of indicators, such as how many carers receive information and how many are referred for a carer's assessment. We have also worked in partnership in Cardiff and Vale to identify the issues that carers say they want to see improved.

Our Key Outcome Indicators are:

- To increase the % of carers who report they have a positive care-life balance
- To increase the % of carers who are involved in decisions that affect them and the person they care for in discharge and care planning
- To reduce the % of carers who report that they have been discriminated against because of their caring role
- To reduce the % of carers who report that they ignore their own physical and mental health symptoms

As the strategy is delivered we will regularly measure our performance against these indicators.

Work has already commenced to meet the aims of the strategy however the full delivery plan will be agreed and implemented once the strategy has been approved by the Welsh Ministers as meeting the requirements under the Regulations. The Strategy covers a 3 year period and will be reviewed after 12, 18 and 24 months and prior to the preparation of the next strategy.

Cardiff and Vale University Health Board will provide an annual report to the Welsh Government on how the Strategy is being implemented and monitored within the geographical areas of Cardiff and the Vale of Glamorgan

### **3. Introduction**

Carers make a significant contribution to the community by providing support to those they care for. It is important that statutory organisations understand and respect the support provided by carers, and work alongside them. Without carers, health and social care services would be under severe pressure.

Carers have a wealth of experience, knowledge and skills that must not be underestimated by statutory services. They should be listened and talked with to help understand both their needs and the needs of the person they care for. To do this requires consulting and involving carers on a planned and ongoing basis, and the Carers Information and Consultation Strategy 2012-2015 will outline how this will be done.

All 3 lead organisations, Cardiff and Vale University Health Board, Cardiff Council and Vale of Glamorgan Council agree that by working together to support carers they will have a better understanding of their needs and will be in a more informed position to offer improved support and services.

The 3 organisations have developed this Strategy to build on the existing joint working between them and with the third sector. Some examples of how organisations already work together are:

- Organising events and stands at various locations to raise carer awareness.
- Cardiff and Vale Councils have shared resources to develop a Carers Emergency Card scheme.
- A Results Based Accountability framework for carers in Cardiff and the Vale was developed by holding joint workshops.
- Cardiff and Vale Councils are working towards joining up their Carers Strategic Planning Groups together with the UHB.
- A joint survey was sent out to known carers in Cardiff and the Vale to create a baseline for this Strategy.

### **4. Purpose of the Strategy**

The purpose of the Carers Information and Consultation Strategy 2012-2015 is to ensure that support for carers in Cardiff and the Vale of Glamorgan is improved.

Our overarching aim is to improve the provision of the support and information that carers need to help them in their role and to make sure that they are involved in decisions about the person they care for.

To do this the strategy will:

- Set out how health services will identify carers as early as possible
- Set out how information will be provided to carers that will assist them in carrying out their caring role
- Set out how carers will be consulted and involved in decisions affecting them and those they care for, and how consent issues affect consultation.
- Demonstrate a commitment to ensuring that:
  - Carers are valued as partners in care
  - Carers are never taken for granted
  - Carers are consulted with in a timely fashion, and their knowledge of the cared for person is treated with respect
  - Carers are made aware of their rights to a needs assessment
  - Assistance is provided to help carers understand decisions if needed
  - Consultation occurs with carers at regular intervals and includes consideration of support needed at short notice
  - Due regard is taken of carers age, including child and young adult carers, and any disability and cultural needs
  - Carers are made aware of support available from voluntary organisations
  - Staff are trained to be aware of carers needs and rights
  - The needs of carers are considered when their caring role ends
  - Support is provided to improve and/or maintain carers' health and wellbeing

## 5. Who are Carers?

The Carers Strategies (Wales) Measure 2010 defines a carer as:

An individual, whether an adult or a child, who provides or intends to provide a substantial amount of care on a regular basis for:

- A child who is disabled within the meaning of Part 3 of the Children Act 1989, or
- An individual aged 18 or over.

“Carer” does not include an individual who provides or intends to provide that care:

- By virtue of a contract of employment or other contract with any person, or
- As a volunteer for any body (whether or not incorporated)

Many carers do not recognise themselves as carers because they see their role as being a spouse, partner, sibling, parent, child, friend or neighbour. They are doing what comes naturally - caring for someone who needs them.

Each caring situation, carer and cared for person is unique. There is no such thing as a typical carer. Carers can live in the same house as the person they care for, while other carers may live nearby and visit regularly. Some may live



a distance away and visit weekly or monthly. Some may visit less often, but call the cared for person every day to make sure everything is ok, or that they've taken their medication.

Care can be provided for limited periods of time or can be a normal part of everyday life. A carer may help out every day, once a week or even sporadically, depending on the nature of the condition.

Carers can quite often be caring for more than one person such as elderly parents and a child with disabilities.

Some carers are in paid employment and cope with the care/work balance, while other may find things more difficult and struggle to combine work, family and caring. Some may even have to give up employment to provide the care.

Carers can be any age, gender or from any background. A significant number of carers are under the age of 18, some as young as 5 years old. Young carers have particular features, they are often hard to identify and are often "invisible" to those who can provide help and support to them.

Because there are so many different aspects to caring, this leads to a large number of 'hidden' carers who are not aware that there may be help and support to them if they need it.

There can be particular problems in identifying carers early enough. This strategy includes carers at all stages of their caring role, and specific emphasis will be placed on supporting health care staff to identify carers as early as possible.

Professional care workers, those providing support as a volunteer with an organisation or agency and family members looking after children who are neither disabled nor have a long-term health condition are **not** defined as carers.

## **6. The Carer Population**

### **6.1 National Statistics**

The 2001 Census identified 340,000 carers in Wales, equal to 11.9% of the population. Research completed by Carers UK, published in May 2011, estimated that the number of carers in Wales had increased by 8% to approximately 370,000.

The 2001 Census also identified 4,600 young carers aged under 18 in Wales, although most authorities believe that the actual number is significantly higher than this and may be as high as 11,000.

The 2011 Census data regarding the numbers of unpaid carers in Wales were unavailable at the time of developing the Carers Information and

Consultation Strategy 2012-2015, and are expected towards the end of 2012. It is anticipated that this data will show an increase in the number of carers, partly because of demographic changes, the increase in the frail elderly population and partly because of increased awareness.

## 6.2 Local Statistics

In order to develop the strategy and the delivery plan it is important to understand the local carer population.

In Cardiff and the Vale of Glamorgan Local Authorities, 45,021 carers were identified in the 2001 census, approximately 10.4% of the population. Based on recently released census 2011 population figures, the population in the two Local Authorities has increased, and if the percentage of carers has remained the same, the number of carers will have increased to approximately 49,000.

There were 1,020 young carers in Cardiff, equating to 1.4% of the population of under 18 year olds.

Detailed information on carer and cared for age, gender, ethnicity and need of the cared for is included as appendix 1 and has been taken from data available from the Cardiff and Vale of Glamorgan social services databases.

In order to obtain additional information, 984 carers listed on registers in the Cardiff and the Vale of Glamorgan Local Authorities were sent a survey in October 2011. The survey excluded young carers. 292 surveys were returned (30%).

The survey asked a number of questions about carers and their role and sought carers views on a number of aspects of caring. The results are summarised in appendix 2.

The UHB has 261 Older Peoples Assessment and Intermediate Care (OPAIC) community hospital beds spread over 5 sites. In late 2011 a census was undertaken of the patients in hospital at that time in order to gain better information about their circumstances to influence the Frail Older People's Service Delivery (FOPSD) Programme (now known as the "Wyn Campaign").

The census did not originally intend to gather information on informal support mechanisms prior to admission however the Census Team noted that informal support was recorded in the notes in at least 120 instances.

Of these, 84 patients had relied on informal carers as their sole support mechanism and 36 to supplement packages of care. In many cases those carers were either spouses or offspring who were themselves over retirement age. In addition, 6 patients were identified as the main carer for someone else.

Of the 120 patients in 59 cases (49%) the case notes indicated that the informal carers had been struggling to cope over a period of time. This had often co-incided with a recorded gradual decline in the patient's condition.

All the above data is essential to shape the Strategy and the delivery plan. An overview of the data shows that

- Female carers outnumber males by 2:1
- The peak age for a carer is between the mid 40s to the mid 60s
- A significant number of carers are over the age of 80
- The peak age for the cared for is over 80
- Carers come from all ethnic backgrounds
- The most frequent needs of the cared for are physical impairment, learning disability, mental health and dementia
- The majority of carers are providing over 50 hours of caring a week
- A significant proportion of people admitted to elderly care wards rely on carers for their support and in a high proportion of these cases the carer is identified as struggling to cope

### **6.3 Parent Carers**

The Cardiff Council Child Health and Disability team is in contact with nearly 800 families whilst the Special Needs Health Visitors are in contact with in the region of a further 250 families. All the families are carers. Some parent carers are as young as 17, some grandparent carers are now in their late 60s. The range of ethnic backgrounds reflects the diversity of the population in Cardiff. About two thirds of the total describe themselves as White British, the other one third include Black African, Bangladeshi, Pakistani, Asian, Indian, Chinese and White European. The children may have severe learning and/or physical disabilities, severe autism, sensory impairments or are receiving treatment for very serious illnesses. The children and young people are almost all aged between 0 and 18 with a small number over 18.

The Vale Child Health and Disability Team are currently working with 147 children and young people with disabilities.

### **6.4 Young Carers**

The precise overall number of Young Carers in Cardiff is not known with a degree of accuracy. Recent research in Cardiff primary schools showed that between 11% - 16% of 10 and 11 year olds from a cohort of 870 pupils in 12 schools were identified as Young Carers.

Cardiff Children's Services are currently working with 79 young carers who meet the children's services eligibility criteria, and the Vale is providing support to 70 young carers. These are children and young people with high levels of need.

Additional information indicates that the majority of Young Carers live in households where the family is dependent on welfare benefits as the sole source of income. The spread of Young Carers will therefore vary greatly across the city with a disproportionate number of children in poorer areas being involved in caring responsibilities.

## **7. Links with Local Carers Strategies and Plans**

Cardiff Carers Strategy was developed in 2010 to cover a period of 4 years. The strategy was developed by Cardiff Council Adult Services, Cardiff & Vale University Health Board and the Cardiff & Vale Carers Centre. The key principles set out in the Cardiff Carers Strategy are:

- Identification, recognition and information
- Involvement and consultation
- Support services
- Carers health and promotion of wellbeing
- Personal development and education
- Employment

In addition Cardiff Council has worked in partnership with young carers and statutory and voluntary organisations to develop a joint Young Carers Strategy to run from 2011 – 2014.

The key outcomes expected from the strategy are

- Young Carers have their needs identified, assessed and met in a timely way by appropriate organisations/ agencies.
- Young Carers are supported to reach their full educational potential and are well equipped to make the transition to adulthood.
- Young Carers experience good emotional and physical health which is not adversely affected by the caring responsibilities.
- Young Carers are able to play and participate in leisure activities with their peers.
- Young Carers feel respected, included and have a voice.

In the Vale of Glamorgan, a Carers Strategy was in place between 2008 and 2011. The strategy covered all carers, including young carers. The intention was to update this in collaboration with Cardiff Council and the Health Board; however this was postponed pending the introduction of the Measure and agreement on future joint planning arrangements between the statutory organisations.

When the Cardiff and Vale University Health Board was formed in October 2009 it was recognised that support for carers needed to be improved. A Carers Action Plan was therefore developed which included a wide range of actions (over and above those subsequently required by the measure) and which covered the period July 2011 to June 2012. Update reports have been provided to the Health Board over that period, with a final report in June 2012.

## **8. Where are we now? - Current Organisational Arrangements**

Over the past few years, there have been a number of changes to how all 3 organisations work with and support carers. This Strategy will help deliver and improve this support.

Recent joint initiatives, including workshops to identify the key outcomes that carers wish to see delivered by the strategy and a carer's survey, have provided evidence that finding relevant information at the right time for carers can be difficult, confusing and time consuming. In most cases information remains hidden, unless a carer knows that it is available. The Carers Information and Consultation Strategy aims to address this.

## **9. Where are we now? - Support for Carers**

Cardiff and the Vale of Glamorgan Councils provide a wide range of support for carers. They both:

- Include carers in the assessment and care planning of the cared for person, including completion of the Carers Perspective Domain of the Unified Assessment.
- Carry out carers needs assessments (Carers Assessments) and provide services to carers following this assessment. Carers Assessments are also reviewed when circumstances change.
- Fund the third sector to provide support services to carers.
- Offer Direct Payment and 'one off payments' to carers to provide services or support directly to them.
- Hold events to provide information and signposting to carers and those working with them.
- Offer Manual Handling training.
- Have a Carers Emergency Card Scheme to provide 'peace of mind' to carers when leaving the person they care for at home alone.

## **10. How the Strategy was Developed**

The statutory duty arising from the Measure requires the UHB and its partners to develop the strategy building on existing partnerships in place through the Health, Social Care and Wellbeing Plans and Children and Young Peoples Plans.

The Integrated Health and Social Care Board (IHSCB) brings together Cardiff UHB, Cardiff Council and the Vale of Glamorgan Council together with the third sector. The key cross boundary/regional issues that are considered are the Frail Elderly, Learning Disabilities, Mental Health and Children with Complex Needs. All of these have key dependencies on carers and therefore are closely involved in the development of the strategy.

A working group, chaired by the UHB Assistant Director Patient Experience was established to develop the strategy in partnership with all the required groups and individuals. The membership is made up of representatives from the UHB, both Local Authorities and third sector organisations, together with carers and the Cardiff and Vale of Glamorgan Community Health Council. At present, the programme manager for the Wyn campaign is a member of the Working Group.

The role of the group is to develop the Carers Information and Consultation Strategy based on their own specialist knowledge and experience and through working with and consulting with stakeholders. The group met monthly during the period February – September 2012.

In order to ensure that all stakeholders were made aware of progress and given the ability to provide feedback the approach adopted was to:

- Produce an accessible briefing after each working group to circulate widely via partners' information and engagement mechanisms. The first issue provided a timetable of strategy development plus the different ways in which people could become involved.
- Have members of the working group attend as many meetings of carers facilitated through the third sector/CHC and Health Board in order to gain views and test proposals. This included seldom heard groups. This utilised existing networks and groups wherever possible.
- Make use of pre-scheduled events to engage with stakeholders, including the Minority Ethnic Community Health Fair in February, Carers' Week Event in June 2012 and Third Sector Health and Social Care Network events.
- Use website pages to inform and receive feedback.

A detailed timeline has been kept throughout the process and this is attached as appendix 3.

A stakeholder consultation event to discuss the draft Carers Information and Consultation Strategy was facilitated at the end of July 2012 by Cardiff Third Sector Council and the Vale Council for Voluntary Services. Thirteen organisations were present and a wide range of views and information was collected. The content has been used to influence the Strategy and will support development of the delivery plan.

## **11. The Cardiff and Vale Carers Information and Consultation Strategy**

The working group identified five linked programmes to deliver the aims of the Strategy. These are described below.

### **11.1 Development of a partnership framework to ensure that the Health Board, Local Councils and the third sector work together to support carers**

## **How will this support delivery of the Carers Information and Consultation Strategy?**

Discussions at the working group and engagement with carers has identified that a significant problem is not so much the lack of information and support that is available for carers as the fact that carers are often not aware of it until it is too late. This is often combined with difficulties navigating a way through the “system”. It is important therefore that all agencies work together to make information more available and accessible to carers.

### **Where are we now?**

Cardiff Council currently has a multi-agency Carers Advisory Planning Group which includes representatives from Adult Services, Health, carers and third sector. It has now been agreed to expand this group in partnership with Vale of Glamorgan Council. This joint group will have its first workshop to develop Terms of Reference etc in September 2012.

Cardiff Council Adult Services is also planning a consultation exercise in the second half of 2012/13 to identify how to improve support and services for carers. The UHB and the Vale of Glamorgan Council will be joint partners in this consultation.

Cardiff Council Adult Services has identified a gap in support for young adult carers (aged 18-24) and will also be running a workshop in August 2012 for young adult carers. The UHB, Vale of Glamorgan Council and Crossroads will be involved and information will be shared with other third sector and statutory organisations.

The Vale of Glamorgan has an active Carers Support and Information Network Group (CSING) which brings together statutory organisations and the voluntary sector. The model is successful and consideration is being given to expanding this to cover the whole of the UHB area.

### **What do we plan to do?**

- In year 1 we will
  - Use a multi-agency, multidisciplinary working group to develop the Carers Information and Consultation Strategy and delivery plan
  - Use the County Voluntary Council networks to brief and engage partners and stakeholders in the development of the strategy
  - Identify and engage with individual carers and groups in the development of the Strategy and delivery plan.
  - Establish a joint Local Authority/UHB/third sector carers planning group

- Work with the Health Board Third Sector Strategic Framework 2012 to enhance partnership working to deliver the aims of the Strategy.
- In years 2 and 3 we will
  - Establish a multi-agency, multi disciplinary networking group to share information and support
  - Establish a local carers infrastructure to support information sharing, identification of best practice and consultation
  - Use the working group to oversee delivery of the Strategy
  - Continue to develop partnership working

## **11.2 Raise awareness of carers, their role and needs to ensure that everyone who needs to be is “carer aware”**

### **How will this support delivery of the Carers Information and Consultation Strategy?**

Although over 2000 carers are included on the databases held by the Local Authorities, this is thought to be only around 4% of the total number of carers. If appropriate support and information is to be provided to carers it is important that all health care staff, and carers themselves are aware of who might be a carer, what they do and what their rights and needs are. It will also support early identification of carers at all stages.

### **Where are we now?**

The UHB has an Independent Member who is the carers' champion. She ensures that carers' interests and issues are highlighted at Board meetings and at other Board Committees. The Board has considered a number of papers about carers' issues and a carer attended a Board meeting in 2011 to present their “story”.

The working group agreed an awareness raising framework which identified the key stakeholders and have monitored progress with engagement against this. The stakeholders included NHS, Council, voluntary and third sector staff, patients, carers and the general public. Key methods of awareness raising were identified and included the media, local and national carers events, carers groups and a range of organisations and inter- and intranet sites.

A mandatory half day Carer Awareness course is already in place for new social work staff in Cardiff Council Adult Services. From May 2012 all new UHB staff receive a short session on carers as part of their induction. In addition the UHB intranet site has been used over the last 12 months to highlight carers' issues.

In the Vale of Glamorgan, all GP practices have a carer's notice board to increase awareness and provide information to carers.



## What do we plan to do?

- In year 1 we will
  - Use key national and local events such as carers week, carers rights day and the Cardiff and Vale Minority Ethnic Community Health Fair to raise awareness of carers' issues
  - Use the media to raise awareness of carers issues and the actions being taken to improve support and engagement
  - Place promotional information in all wards, departments and clinical areas to raise awareness amongst staff and carers
  - Work with General Practices to raise awareness amongst staff and patients of carers' issues
  - Start to collect and use carers stories to raise awareness of carers and their issues
  - Introduce a range of other measures such as a dedicated email address for carers to contact the UHB, a dedicated issue of the UHB newsletter focusing on carers and access to carers support information directly from UHB clinical workstations.
  - Issue all Health Board staff with a briefing on carers with their pay slip
  
- In years 2 and 3 we will
  - Continue to use national and local events to raise awareness
  - Work with GP practices, Community Pharmacies and other contractor services to review the learning from previous projects and identify the best way to maintain awareness amongst patients, staff and carers
  - Continue the use the media to raise awareness
  - Explore the introduction of "carers' champions" in wards and other clinical areas

### **11.3 Implement an education and training framework, to ensure that the training needs of healthcare staff and carers are identified and met**

#### **How will this support delivery of the strategy?**

Although the awareness raising strategy will play a part in ensuring that appropriate support, information and consultation with carers takes place, an educational framework will ensure that the level of knowledge of staff is uniform and at the correct level for the roles that they undertake. A three tier framework will range from basic awareness to more detailed understanding of carers' issues. In addition, there is a need for carers themselves to have access to education and training, including aspects of physical care such as skin integrity, nutrition, demonstrations of equipment and also their own emotional considerations such as stress resilience.

## **Where are we now?**

The working group has identified the current training that is undertaken within the Local Authorities. Based on this and an assessment of the needs of UHB staff and carers a three level training framework has been developed.

### **Level 1 Carer Aware**

This programme would be aimed at all staff UHB, Local Authority, third sector staff and volunteers, and contractors who have an interest in carers' issues.

Outcomes of the programme would be to enable staff to

- Define what is a carer is
- Understand carers rights
- Identify and recognise carers issues
- Signpost accordingly

The course would be delivered as part of induction/mandatory training, integrated into other training opportunities and within primary care settings and delivered through e learning, and/or a PowerPoint presentation.

### **Level 2 Carer Identification and Support**

This programme would be targeted at qualified staff from all disciplines in the UHB, third sector managers and relevant independent contractors.

The aim of the programme would be to

- Ensure staff are able to signpost or provide information
- Involve carers in relation to ongoing care/discharge planning care issues
- Signpost carers to education and training such as
  - Safe lifting
  - Help with eating and drinking
  - Hygiene
  - Administering Medicines

The programme would be delivered by UHB trainers and others, including third sector staff via classroom based programmes ideally integrated into existing work streams of other programmes and via e-learning.

### **Level 3 Complex Needs and Caring**

This programme would be for staff who are working closely with people who are undertaking complex caring roles. For example caring for those

with physical and mental health issues requiring a high level of skill to maintain those cared for in their own environments.

The programme would build on level 1 and 2 and will be delivered by UHB Trainers, and others including the third sector, via classroom based initiatives and e-learning.

### **Caring for Carers**

This would be a programme delivered for carers to enable them to understand their rights as carers and fulfil their caring role to the best of their ability, taking into account their own health issues. The outcomes would be that carers feel informed and able to undertake safely, their caring role, feel supported and empowered. The content of the programme may include issues such as manual handling, nutrition and hydration, skin care, self care and welfare rights. It would integrate and enhance existing programmes.

The working group has sought the views of carers through an online and paper survey on their information and training needs and the best ways to meet them. The information from this survey has helped prioritise training needs of carers.

### **What do we plan to do?**

- In year 1 we will
  - Agree an education and training framework for UHB staff to ensure they are able to fully support carers
  - Scope and identify the number of staff to undertake each level
  - Develop a range of programmes to meet the educational aims, incorporating carers themes and information into existing programmes where appropriate
  - Develop an e-learning level one training module which can be accessed by UHB staff
  - Develop a prospectus drawing together courses and training sessions appropriate for carers and staff
  - Work with the Education Programmes for Patients team to increase access to the "Looking after Me" carers programme
  - Pilot a healthcare forum for carers which brings together staff with expertise in the topics identified by carers as priority areas
  
- In years 2 and 3 we will
  - Deliver training and education programmes in line with the framework
  - Aim to run quarterly health care forums for carers based on the pilot
  - Develop a stress resilience programme for carers

- Work with undergraduate schools of medicine, nursing and other

#### **11.4 Develop carers pathways to identify the information, support and consultation that carers need throughout their time as a carer**

##### **How will this support delivery of the Carers Information and Consultation Strategy?**

The Strategy recognises that early identification of carers is a key part of improving the provision of support and information for carers and to ensure that they are involved in decisions about those they care for. Clear pathways will support UHB staff to do this. It is recognised that the majority of first contacts with health services are with General Practice and the pathways will address this.

##### **Where are we now?**

The GMS Quality Outcomes Framework (QOF) - Practice Management Indicator 9 states “The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment”. Cardiff and the Vale UHB GP practices achieved 100% compliance with this indicator in 2011-12. Therefore all 67 GP practices have a protocol in place.

The protocols vary across the Health Board, with practices listing their involvement in both encouraging patients to provide “self identification” and “practice identification”.

As part of the “self identification” process, practices are able to provide information and reminders for patients in a number of ways. This includes information and reminders on notice-boards and displays in waiting rooms, reminders on prescription forms, self referral forms, reminders on websites and patient information leaflets and reminders on new patient registration forms.

As part of the “practice identification” process, practices are able to put reminders in patients’ letters and questionnaires (e.g. as part of the flu vaccination campaign), prescription forms or health professional identification. The protocols also include the process for referral to the Carers Centre. The information leaflets available vary across practices.

In order to “mainstream” consideration of carers into hospital based clinical practice we have developed a pathway for carers during an in patient admission of the cared for person. It describes actions that clinical staff should take to identify, involve and provide information and support to carers at admission, during the hospital stay and at discharge. The pathway is based on discussions with carers, sisters and charge nurses and in conjunction with a review of the discharge process. The carer’s pathway for in patients includes the need to seek and document consent for the sharing of information with carers. This

will include medication, treatment and practical issues relating to care at home and long term care. It will also address issues relevant to Mental Capacity.

The pathway will be made available on each ward and will be used in conjunction with the education and training programme.

The need to involve carers in the discharge process is an integral part of the Health Board discharge policy, and ensuring the involvement of carers will continue to be a major focus as implementation of the policy is reviewed and further developed

The working group has also identified several areas of existing good practice in the UHB, including in mental health services, stroke services and the memory clinic. The learning from these areas will be used to support development of best practice across the UHB.

### **What do we plan to do?**

- In year 1 we will
  - Introduce the in patient pathway at ward level and integrate it into the education and training programme
  - Revise our discharge documentation for staff to ensure they support full involvement of carers in the process
  - Start work with General Practices to identify and share best practice
  
- In year 2 we will
  - Review the impact of the in patient pathway on staff and carers
  - Develop additional pathways to describe the support and involvement of carers throughout all their contacts with Health Services
  - Work with other partners, including Velindre NHS Trust and the Wales Ambulance Services Trust to integrate the identification and provision of support to carers.
  - Review the all Wales dataset for nursing documentation and ensure that local implementation addresses the needs of carers
  - Review our discharge documentation based on experience in year 1
  
- In year 3 we will
  - Continue to review the impact of the pathways on staff and carers
  - Develop additional pathways to describe the support and involvement of carers throughout all their contacts with Health Services

- Review the documentation for admission and discharge to ensure it meets the needs of carers

### **11.5 Provide an information framework, to ensure that all carers are provided with appropriate information at all stages of their caring pathway**

#### **How will this support delivery of the Carers Information and Consultation Strategy?**

The provision of the right information, in the right format, in the right place and at the right time is an essential component of the support that carers need. Carers often say that they wished that they had received information sooner. They also say that there is a need for someone to be available to support them in identifying their information needs. This framework will identify three levels of information – that for the general public, an A-Z of support agencies to be made widely available for carers and staff and “Carers Packs” for individual carers.

#### **Where are we now?**

A wide range of accessible information is currently available to carers and the general public in the Health Board. Cardiff and the Vale of Glamorgan Councils have carers’ handbooks available. These are available through the respective web sites and copies are given to each carer when identified at enquiry or through the assessment process. Cardiff Council has an A-Z of voluntary sector and other support and information services and VCVS have compiled an A-Z for the Vale of Glamorgan. In addition, NHS Direct, Cardiff and Vale Carers Centre and a wide range of third organisations provide information. All dispensed medications contain a patient information leaflet (PIL) produced by the drug manufacturer containing information such as usage, dosing, side-effects etc.

The guidance issued to Local Health Boards, NHS Trusts and Local Authorities by the Welsh Government in December 2011 included suggestions for a wide range of information that should be considered for provision to carers, the format in which it could be provided and the agencies who could provide it. In order to seek the views of local carers and stakeholders the following actions have been undertaken:

- A workshop at the Carers Week conference in Cardiff in June 2011 asked carers to highlight their information and support needs and desired outcomes from increased support from the Health Service
- The issues were discussed at a number of meetings with carers groups throughout 2012, and at other events run by third sector and other partners. These included the Health Fair held for carers in Cardiff during Carers’ Week in June 2012 and at the celebration event for carers in the Vale of Glamorgan during the same week.

- A survey was made available to carers during carers' week 2012, both online and in paper form which sought feedback from carers on how and where information should be made available
- Enquiries made by carers to the weekly stall held by the Cardiff Branch of Carers UK have been reviewed, together with those made to the Macmillan Information Centre at UHW.

The feedback and information gained has influenced the priorities and content of the Carers Information and Consultation Strategy.

The contact points for local support agencies and the relevant national organisations have been identified through collaboration with the Cardiff Third Sector Council (C3SC) and Vale Centre for Voluntary Services (VCVS), NHS Direct, Cardiff and Vale Carers Centre individual carers and other voluntary organisations. Links to these are now available to NHS staff through a number of access points, in electronic and hard copy form, including information racks on wards and clinical areas. The new Macmillan Patient Information Centre at UHW includes information for carers, as do the Citizens Advice Bureau clinics now held at University Hospital of Wales and University Hospital Llandough.

The working group has reviewed the list of recommended information that should be available to carers and has identified current providers and where there may be gaps.

### **What do we plan to do?**

- In year 1 we will
  - Use the “three level” approach to structure the provision of information within the UHB and in the two Local Authorities.
  - Review the needs of all carers, including those from Minority Ethnic Communities, those with sensory impairment and those with low literacy levels, to identify the most appropriate ways to ensure access to information
  - Review the information needs of Young Carers and explore the best methods of designing and delivering this
  - Increase the number of locations in the Health Board where information for carers is available, including hospital public areas, hospital information centres, wards and departments and general practice
  - Increase the provision of advice available in hospital sites, including the Macmillan Cancer Information Centre at UHW, Citizens Advice Bureau clinics at UHW and UHL
  - Introduce a generic leaflet aimed at the public outlining the role of carers and their rights
  - Develop a joint carer's handbook between the two Local Authorities and the Health Board, to include the recommended range of information identified in the guidance. Where it is not

- possible to include information in this form, separate literature and signposting will be made available
- Develop a joint A-Z directory of voluntary sector and other support and information services
  - In year 2 we will
    - Introduce the joint carers handbook across the Health Board and Local Authorities
    - Make provision for access to information by all carers irrespective of their language, disability or literacy level
    - Make provision for access to appropriate, relevant information for Young Carers
    - Incorporate awareness and use of the information amongst Health Service staff to ensure they are able to support and signpost carers appropriately according to their needs
    - Review the response to the newly developed information and update materials as necessary
    - Work with local and regional information providers to put in place a virtual network of face to face information provision, advice and support
    - Further increase the provision of advice centres in hospital sites, including Barry Hospital and UHL and work with partners to identify other locations in the community.
  - In year 3 we will
    - Continue to review the content, use and response to the information and revise as necessary.
    - Explore the use of new technology, including smartphones and the internet to enhance availability and access to information
    - Further increase the provision of advice centres in hospital sites and in the community

## 12. Young Carers

Cardiff Young Carers have provided the following definition of a Young Carer based on their personal experiences.

*“A young carer takes responsibility for someone who is ill, disabled, elderly, experiencing mental distress or affected by substance miss-use, or has substantial responsibility for caring for a sibling or relative.*

*A young carer could be from any family and is under the age of 18. They may be providing all of the care or helping someone else to provide care.*

*The care they provide is not only the things you see like cooking, cleaning, changing bandages or helping someone with the toilet, it's also the things you can't see, how a carer thinks or feels about their caring role”.*



For the purpose of the Carers Information and Consultation Strategy, Young Carers are defined as children and young people who are under the age of 18 who have caring responsibilities for someone who has a physical or mental illness, a physical or learning disability, or drug or alcohol problem. The person they look after may be a parent, a brother or sister, a grandparent or other relative. They may provide practical or physical care, help with personal care, and help with domestic tasks and/or emotional support.

Young Carers undertake a range of caring tasks:

- **General care** such as giving medication, changing dressings, assisting with mobility
- **Domestic tasks** such as cooking, cleaning, washing, ironing, shopping
- **Emotional support** – supporting people through distressing life-threatening, life-limiting and mental health conditions
- **Intimate care** – dressing, washing and helping with toilet requirements
- **Child Care** – helping with younger sibling in addition to other caring tasks
- **Other** – helping with household and other administration tasks, bill paying, accompanying to doctors or hospital etc

Research provided from a number of sources confirm that the nature and extent of the caring tasks are, in the main, determined by the condition of the cared for person and family circumstances. This can impact on the health and social development of the Young Carer. Young Carers often miss out on many everyday activities that other young people take for granted. The impact of this is:

- Limited opportunities
- Educational problems
- Bullying
- A lack of understanding from peers and restricted friendships
- Isolation, a feeling of exclusion and being outsiders
- Stigma by association, related to physical impairment and in particular mental health
- Fearing what professionals might say or do
- Living with silence and fears
- Health and emotional difficulties including self harm
- Unexpected and early rise to adulthood often resulting in difficulties in transition to becoming an adult
- Opportunities for older Young Carers for further/higher education are restricted and their employment opportunities are adversely affected

The working group has recognised that the needs of Young Carers may be different from that of the adult population. Although the whole strategy applies to young carers where appropriate, it has been recognised that specifically for Young Carers actions will include:

- Clarifying and enhancing the mechanisms in place in the UHB and Local Authorities to identify and support Young Carers and ensuring that this information is shared as appropriate.

- Raise awareness of issues facing Young Carers through training of frontline staff, to include School Nurses, Health Visitors, District Nurses, General Practitioners and their teams etc.
- Identifying ways of assessing the dynamics of the family situation facing Young Carers such as:
  - If an adult who is being cared for is admitted to hospital, what is the impact on the Young Carer?
  - Are single adults with children asked what arrangements are in place to care for them?
  - If Young Carer is admitted, what alternative caring arrangements are made?
- Development of a Health Board wide pathway for identification and supporting Young Carers

These actions will be taken forward as part of the strategy and in collaboration with the Young Carers Strategy.

### **13. Involvement of Carers in Consultations Regarding Service Change**

The UHB believe that patients and their carers have an important voice that should be heard and it tries hard to include patients and the public in the development of options and decision making, where possible, to ensure that the services provided truly meet the needs of those who use them. It is also recognised that it is important to people that if they get involved and take part in consultations they see how their contribution has helped to develop healthcare services.

The UHB is in the process of developing a coherent corporate approach to Engagement and Consultation as a key response to '*Guidance for Engagement and Consultation on Changes to Health Services*' published in March 2011 by Welsh Government. This Guidance requires organisations to place a much greater emphasis on continuous engagement and the UHB is committed to embedding this approach into the way all service areas conduct their business. Carers are recognised as key partners in this, as highlighted by the inclusion of a member from a third sector carer organisation on the UHB Stakeholder Reference Group (SRG), providing a specific carer perspective on the issues considered by the Group. The SRG provides a forum for early engagement and involvement in the determination of UHB overall strategic direction, provision of advice on specific service proposals prior to formal consultation and feedback on the impact of UHB operations on the communities it serves.

Another 'structural' mechanism for facilitating the involvement of carers in UHB planning and decision making is through the UHB's relationship with the third sector. The UHB funds a health and social care facilitator in each County Voluntary Council and this supports practical mechanisms for accessing carer organisations and service users. The UHB has also recently developed a

Strategic Framework for Working with the Third Sector, which further embeds a collaborative approach into core business.

#### **14. Monitoring Progress**

The Welsh Government has issued provisional headline performance indicators to accompany the Measure. These are:

- % of carers identified by the partnership
- % of staff within the partnership area who have undertaken training
- % of carers who have been referred for an assessment
- % of carers who take up an assessment

The working group will identify baseline data and processes for providing information as required to track progress, and will participate in the planned further development of the outcomes framework.

The local Results Based Accountability process, developed jointly between the UHB, the two Local Authorities, third sector organisations and stakeholders, has identified the four key indicators that will be used to measure progress in improving support for carers. These are:

- % of carers who report they have a positive care-life balance
- % of carers involved in decisions that affect them and the person they care for in discharge and care planning
- % of carers who report that they have been discriminated against because of their caring role
- % of carers who report that they ignore their own physical and mental health symptoms

In order to gain baseline information for the indicators a survey of carers in Cardiff and the Vale of Glamorgan was carried out in October 2011. The results are shown in Appendix 2.

The information gained in the survey will act as a baseline against which improvements achieved through the action plan and Carers Measure can be assessed.

The working group has agreed that the survey should be run at annual intervals throughout the duration of the strategy.

The working group has recognised that the indicators will need revision to be appropriate for young carers and the development work for this will be undertaken in collaboration with the new joint planning group and the Cardiff Young Carers Strategy implementation. A specific survey for young carers will be undertaken to provide baseline data.

## **15. Equality Impact Assessment**

The working group has recognised that the Carers Information and Consultation Strategy will impact on carers and the cared for in the whole population of Cardiff and the Vale of Glamorgan.

The Strategy has undergone an Equality Impact Assessment (EIA) in the UHB and each of the statutory partners has undertaken their own. This has considered the potential impact on all carers, irrespective of age, disability, race, skin colour, nationality, language, sex, sexual orientation, marital status, religion or beliefs.

The EIA has shown that whilst carers as a group can be disadvantaged, there are specific features of those with the protected characteristics which need to be addressed. This will be a key component of the delivery plan. The Strategy aims deliver improvements for all carers and the delivery plan which will be developed based on the strategy will ensure that these principles are met for the whole population.

## **16. Next Steps**

The working group has commenced the process of developing delivery plans for the work streams and will oversee their implementation. Following acceptance of the Strategy by the Welsh Government regular update reports will be provided for the three statutory bodies and stakeholders.

## Demographics of Carers in Cardiff and the Vale of Glamorgan

**Table 1**  
**Age of Carers in the Vale of Glamorgan**

Carer Age Groups	Number
<18	3
18-64	265
+65	210
Not recorded	63
<b>Total</b>	<b>541</b>

**Table 2**  
**Gender of Carers in the Vale of Glamorgan**

Carer Gender	Number
Male	150
Female	384
Not recorded	7
<b>Total</b>	<b>541</b>

**Table 3**  
**Ethnic Origin of Carers in the Vale of Glamorgan**

Carer Ethnic Origin	Number
A1 - White - British	400
A2 - White - Irish	2
A3 - White - Any other White background	9
B1 - Mixed - White and Black Caribbean	1
C1 - Asian/Asian British - Indian	2
C3 - Asian/Asian British - Bangladeshi	1
C4 - Asian/Asian British - Any other Asian background	1
D1 - Black/Black British - Caribbean	1
D3 - Black/Black British - Any other Black/ African / Caribbean background	2
E1 - Chinese	1
Disclosure Declined	3
Not Recorded	118
<b>Total</b>	<b>541</b>

**Table 4**  
**Age of Cared For Person in the Vale of Glamorgan**

Cared for Age Groups	Number
<18	5
18-64	365
>65	425
Not recorded	41
<b>Total</b>	<b>836</b>

**Table 5**  
**Needs of Cared For Person in the Vale of Glamorgan**

Cared for Person Main Category	Number
Not Recorded	340
UA - Physical/Sensory Disability/Frailty	274
UA - Carer	53
UA - Mental Health	25
UA - Dementia	22
UA - Learning Disability	22
UA - Other Vulnerable People	5
UA - Substance Misuse	2
ICS - Carer	85
<b>Total</b>	<b>828</b>

\* based on UA carers assessments completed

**Table 6**  
**Age of Adult Carers in Cardiff**

Carer Age Groups	Number
18-24	16
25-34	32
35-44	93
45-59	347
60-79	387
>80	170
Not recorded	250
<b>Total</b>	<b>1295</b>

**Table 7**  
**Ethnic Origin of Carers in Cardiff**

<b>Carer Ethnic Origin</b>	<b>Number</b>
Asian	12
Bangladeshi	8
Black African	10
Black British	7
Black Caribbean	3
Black (other background)	2
Chinese	6
Indian	11
Pakistani	7
White and Asian	1
White and Black African	2
White and Black Caribbean	2
White British	739
White Irish	3
White European	11
White (other background)	14
Other ethnic origin	3
Not recorded/declined	424
<b>Total</b>	<b>1295</b>

**Table 8**  
**Needs of Cared For Person in Cardiff**

<b>Cared for Person Main Category</b>	<b>Number</b>
Not Recorded	68
Mental Health (older people)	80
Learning disability	175
Mental Health	78
Physical impairment/elderly	866
Sensory Impairment	25
Substance misuse	3
<b>Total</b>	<b>1295</b>

**Table 9**  
**Age of Cared For Person in Cardiff**

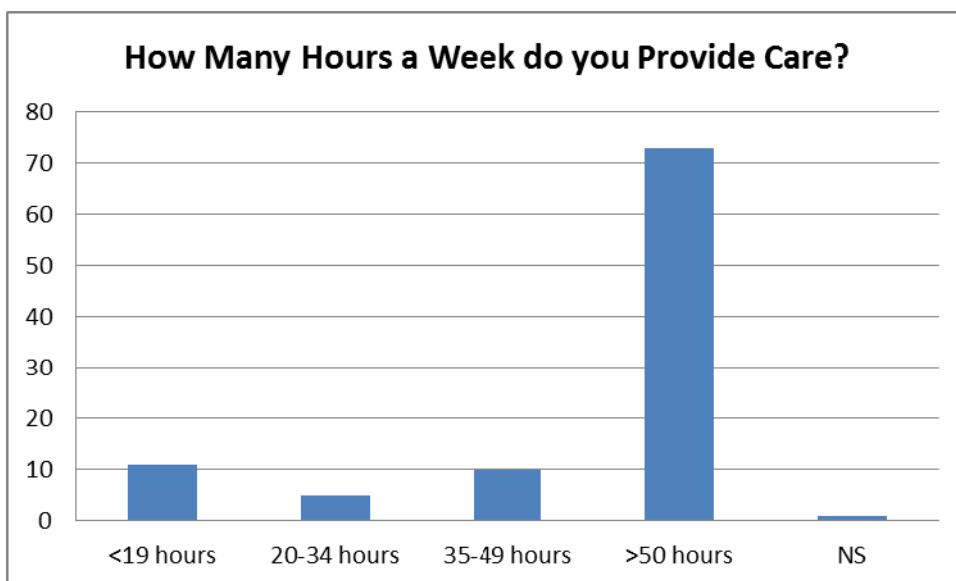
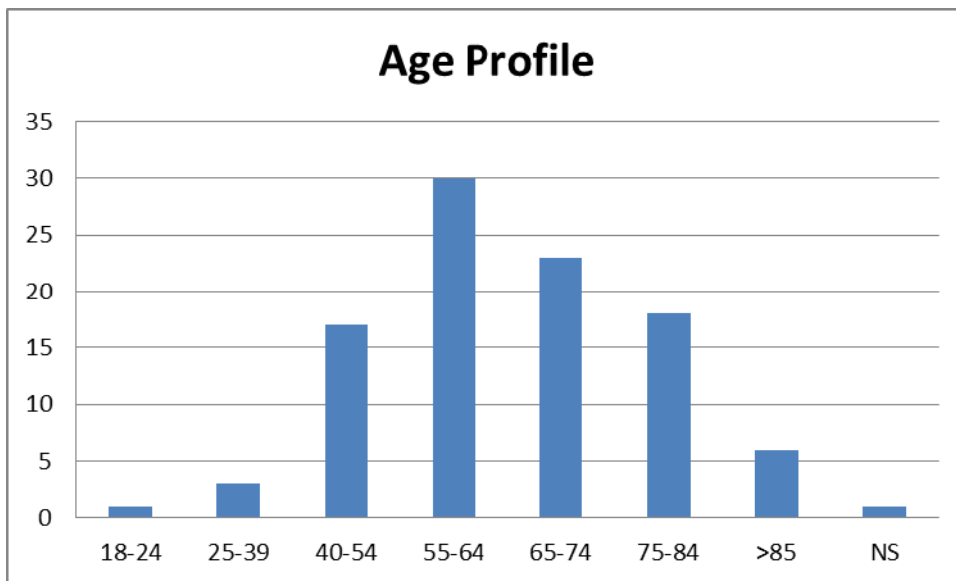
<b>Cared for Age</b>	<b>Number</b>
18-24	95
25-34	77
35-44	80
45-59	133
60-79	332
>80	566
Not recorded	12
<b>Total</b>	<b>1295</b>

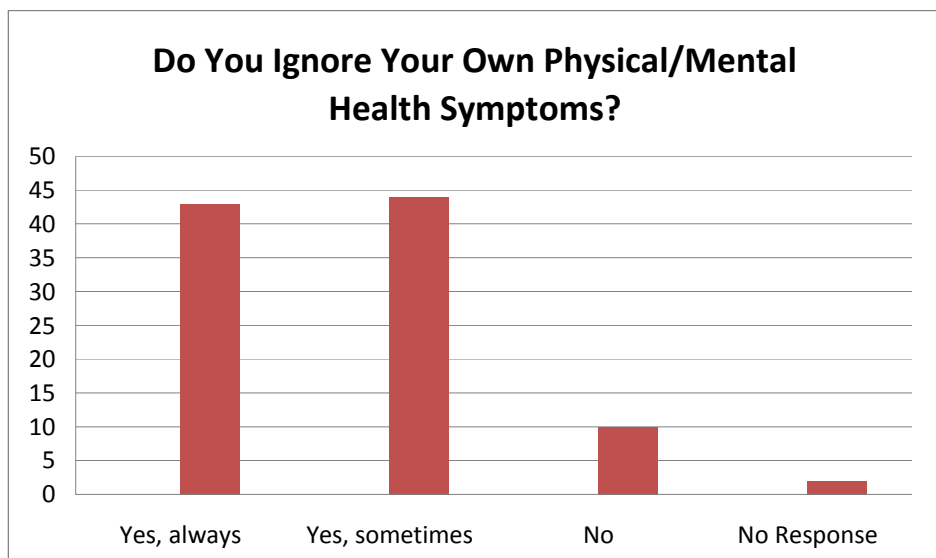
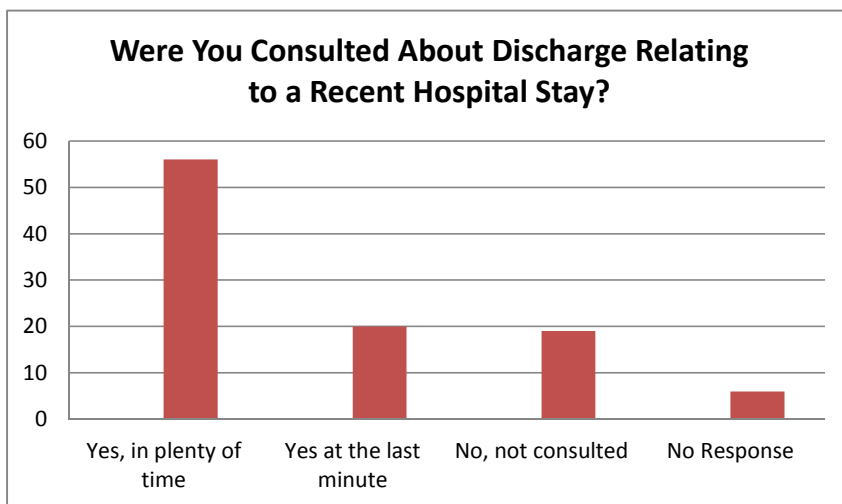
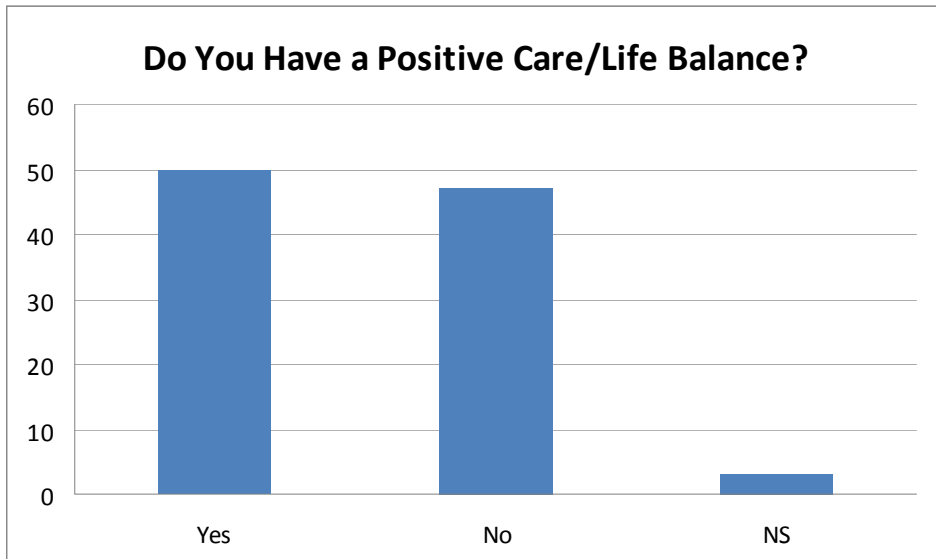


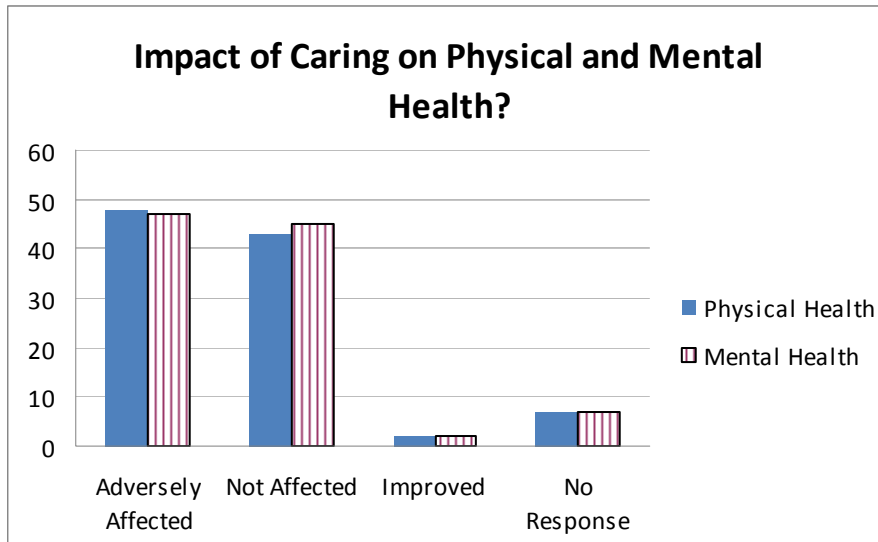
**CARERS SURVEY October 2011**

984 carers listed on registers in the Cardiff and the Vale of Glamorgan Local Authorities were sent a survey in October 2011. The survey was based on a survey undertaken across the United Kingdom by Carers UK in 2010 and included a number of locally determined questions, based on the key indicators identified as part of the Results Based accountability process. The survey was piloted as part of carers' week in July 2011. The survey excluded young carers and this will be addressed in other ways.

292 surveys were returned (30%). A summary of some key indicators is shown below.

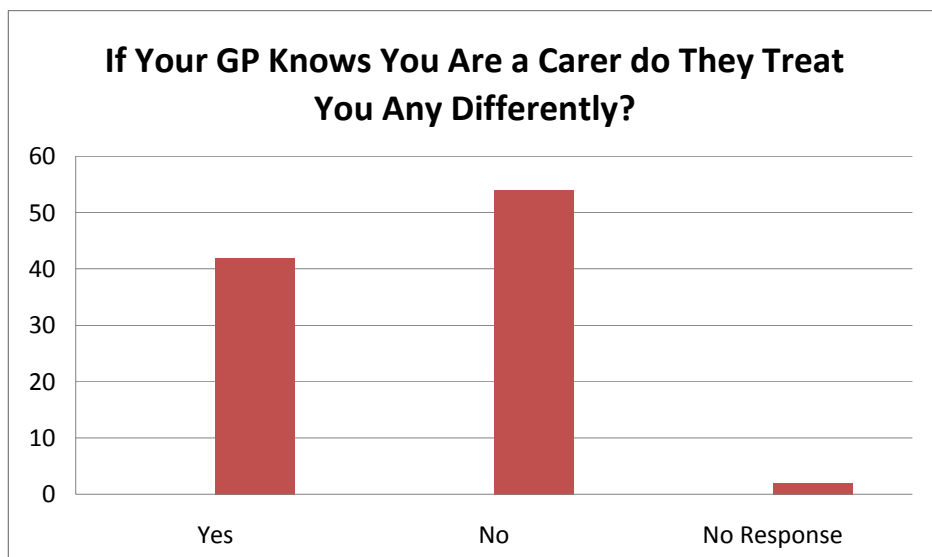






76% of respondents indicated that their General Practice knew that they have caring responsibilities. They were also asked if the practice offered extra support or treated them differently in the light of this knowledge.

42% answered yes and the support offered most frequently was joint appointments, home visits and telephone appointments (21-23% of respondents). However, less than 4% were offered advice on financial and practical support or offered local support group or voluntary organisation information.



The information gained in the survey will act as a baseline against which improvements achieved through the action plan and Carers Measure can be assessed. The results of the key RBA indicators were:

- 50.0% said that they had a positive care life balance

- 56.0% of carers said that they were appropriately involved in decisions about discharge
- 87.0% said that they did ignore their own physical and mental health symptoms because they prioritised the health of the person they cared for
- 9.0% said that they had been disadvantaged with regard to Health Services because of their caring role
- 11.0% said that they had been disadvantaged with regard to other services because of their caring role
- 10.0% said that they had been disadvantaged with regard to employment because of their caring role
- 8.0% said that they had been disadvantaged with regard to education because of their caring role

**OUTLINE TIMELINE – CARERS STRATEGY DEVELOPMENT**

February		21 <sup>st</sup> - 1 <sup>st</sup> meeting of Working Group. Agreed Terms of Reference, reviewed information content template, agreed modus operandi
		27 <sup>th</sup> – Carers stand at Cardiff Minority Ethnic Community Health Fair
March		12 <sup>th</sup> – Young Carers Task Group
		14 <sup>th</sup> - 2 <sup>nd</sup> meeting of Working Group, agreed awareness raising strategy, training and education plan, role of GPs
		15 <sup>th</sup> – Discussion at Cardiff Carers APG
April		18 <sup>th</sup> – Stall at Vale of Glamorgan Disability Index Event
		18 <sup>th</sup> - 3 <sup>rd</sup> meeting of Working Group. Agreed carer awareness at UHB staff induction, placement of carer leaflet racks in clinical areas, in-patient carer pathway document, plans for Citizens Advice Bureau welfare sessions/Information Kiosks at UHW and UHL, reviewed indicators to assess impact of measure
May		Inclusion in Vale of Glamorgan Carers Newsletter
		14 <sup>th</sup> - Young Carers Task Group
		22 <sup>nd</sup> - 4 <sup>th</sup> meeting of Working Group. Agreed development of Carers Directory for Cardiff and VOG, role of Communications Hub in identification of carers
		Online survey for carers developed
June		18 <sup>th</sup> - Taking Care of Yourself event for Carers Week for carers in Cardiff and Vale of Glamorgan. Consultation via Carers survey and briefing document
		19 <sup>th</sup> - Duffryn Event for carers in the Vale of Glamorgan
		18 <sup>th</sup> – 22 <sup>nd</sup> Attendance at other Carers Week events
		Carers Strategy update report to UHB Quality and Safety Committee
		22 <sup>nd</sup> - 5 <sup>th</sup> meeting with Group – Discussion of first draft of Strategy (1)
		Carers survey circulated to 3 <sup>rd</sup> sector via C3SC and VCVS

July		9 <sup>th</sup> – Young Carers Task Group – agreed chapter on Young Carers in Strategy
		19 <sup>th</sup> – Meeting with CHC Carers Group at St David's Hospital
		24 <sup>th</sup> - 6 <sup>th</sup> meeting with Group – Draft Strategy (2)
August		7 <sup>th</sup> meeting of working group to consider final draft and commence development of delivery plan
		Commence development of plans to publish and translate strategy and develop “easy read” version
September		4 <sup>th</sup> – Draft Strategy to UHB Board for discussion , and to the two Local Authorities
October		Strategy to be submitted to Welsh Government, Strategy to be published