West Yorkshire & Harrogate

Health and Care Partnership

Report of findings carers and primary engagement event

September 2018

West Yorkshire and Harrogate Health and Care Partnership

Report of findings
Carers & Primary Care Engagement Event

25 September 2018

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1. Purpose of the Report

The purpose of this report is to present the findings from the West Yorkshire and Harrogate (WY&H) Health and Care Partnership (HCP) carers & primary care engagement event which took place on Tuesday 25 September at Clayton Hotel Leeds in Leeds.

This report describes the journey so far, the purpose of the event, the content of the session and the feedback we received from health care professionals. The report also sets out the legal obligations for engagement and the principles by which WY&H Heath and Care Partnership want to engage, which is in line with the partnerships strategy.

2. Background

West Yorkshire & Harrogate Health and Care Partnership have been recognised by NHS England as an exemplar site for developing support for unpaid carers.

We estimate that there are around 260,000 carers in West Yorkshire and Harrogate. As public services continue to face financial pressures, increasing demand, the introductions of new legislation and approaches, and changing expectations of citizens, increasing numbers of unpaid carers are taking on responsibility for more intensive levels of care. This combined with changes in retirement age, means the demographic of unpaid carers across the country is changing too. This will become more complex as the changes in retirement age means people will be working until much later than is currently the case and therefore juggling work and caring for longer.

Across our area there are a significant number of working carers, many of whom struggle to cope with managing their caring responsibilities alongside work. There is also evidence that people who are carers can have poorer health than those who are not. We aspire to be a place where working carers are recognised and supported to remain in work.

Although caring can be rewarding, there is substantial evidence that carers have poorer physical and mental health than those who are not caring, and that the more care you provide the more likely you are to have poorer health. For many carers, the biggest priority is the health and wellbeing of those they care for and as such they are more likely to neglect their own health and are known to put off treatment for themselves.

As a partnership we recognise that carers play a significant role in delivering and supporting health and care and that without them the health and care system would be overwhelmed. Carers are recognised in a number of partnership work-streams and our next steps document. We want to raise their profile and share the excellent work taking place across the area.

In addition we also want to celebrate the difference this is making in our communities on a regional and national level – and most importantly ensure that this is applied for all carers no matter where they live in West Yorkshire and Harrogate.

"We aspire to be a place where carers are identified, recognised and supported"

2.1   Purpose of the event

While most carers are not known, for example to social care services, an estimated 90% access a primary care service either visiting with the person they care for and/or for themselves. This means that primary care services are ideally placed to identify carers, to register them and to link them to the information and support that is available locally.

Early identification and support through contact with primary care can enable carers to cope better to ensure their own health does not deteriorate which in turn means they are more able to continue in their role as partners in patient care.

However, a failure to support carers effectively is likely to result in a deterioration of their health meaning they are less likely to be able to continue caring and more likely to present as unwell in a GP surgery.

"Our vision is to support Primary Care services to identify carers routinely and to signpost them to relevant information, advice and support"

In order to achieve this vision we aim to:

- Ensure there is a consistent approach across West Yorkshire and Harrogate to routinely identify carers, and signpost them to local and national information, advice and support services
- Work in collaboration with NHS England to develop quality indicators for carers in primary care
- Support John's campaign with primary care, encourage carers to remain during consultations of patients living with dementia.
- Prevent and delay carer 'burn-out' and/or 'breakdown' which results in both the cared-for person and the carer accessing and becoming dependent on formal health and care services

The event, supported by NHS England, focused on improving the quality of life and well-being of the 260,000 carers living across the area.

Every effort should be made to engage and increase awareness of the role of carers within the West Yorkshire and Harrogate Health and Care Partnership. This will help to ensure support for carers is given the recognition and profile it deserves within all the work streams of the partnership.

3.   Principles for Engagement

Our draft communications and engagement strategy sets out our principles for communications, engagement and consultation and our approach to working with local people. Engaging and communicating with partners, stakeholders and the public in the planning, design and delivery is essential if we are to get this right. We are committed to transparency and meaningful engagement in our work.

We are also committed to meaningful conversations with people, on the right issues at the right time. We believe that this approach informs the ambitions of our partnership - to work in an open and transparent way with communities.

The strategy can be found at http://www.wyhpartnership.co.uk/get-involved and sets out what the public can reasonably expect West Yorkshire and Harrogate Health and Care Partnership to do as part of any engagement activity and the process required to preserve these principles to ensure public expectations are met.

Key drivers and legal obligations can be found in appendix 1.

4.   What we already know

The information below has been taken from the presentations given at the unpaid carers event by NHS England, Public Health England, Wakefield and Carers UK.

National context
- Many carers are hidden i.e. providing the majority of care without support
- Three quarters of carers feel that their contribution is not understood or valued by the government
- The value of unpaid care, carers give in the UK is £132bn a year - This compares with a value of health spending in the UK at £134bn a year
- There are 6.5 million carers in the UK and the number is getting bigger
- 1 in 8 adults are carers
- 1 in 12 children and young people are carers
- 1.8m carers aged 60 and over in England including 151,674 between the ages of 80–84
- and 87,346 over the age of 85
- Every day another 6,000 people take on a caring responsibility – that equals over 2 million people each year
- It is expected that the demand for care provided by spouses and adult children will increase by around 60% by 2030
- Over 3 million people juggle care with work, however the significant demands of caring mean that 1 in 5 carers are forced to give up work altogether
- Low number of known young carers – challenge in responding to the statutory duty to take reasonable steps to identify and offer assessments to young carers.
- Young carers miss on average 48 full or part school days per year
- Young adult carers aged between 16 and 18 years are twice as likely to be NEET
- 68% of young carers report that they are bullied in schools
- People providing high levels of care are twice as likely to be permanently sick or disabled
- 625,000 people suffer mental and physical ill health as a direct consequence of the stress and physical demands of caring
- 6 out of 10 carers said their physical health has worsened as a result of caring;
- 7 out of 10 said they have suffered mental ill-health.
- 51% of the public say they don't know anyone is carer

- 62% of workers say they don't know a single colleague who is a carer
- Carers UK have solid evidence that:
    - Carers are twice as likely to be in bad health as non-carers –Census 2011
    - 70% of carers have poorer mental health (2017)
    - 61% say physical health has deteriorated (2017)
    - 54% have reduced exercise
- 2 million giving up work to care
- Early help reduces carer breakdown, limits support needed over the long term
- Investment can contribute to the sustainability of healthcare

The argument for change nationally is:
- If effective support is provided to carers, then the carer's health status will improve: they may require less health and social care
- If effective advice to carers and employers is provided, then the carer will be more able to remain in work
- If effective support is provided to carers, then the person with care needs will be better supported: they may require less health and social care

Local context

There are around 260,000 unpaid carers across WY&H. This is split across WY&H as follows and equates to 9.79% of the population. These numbers are people identified in the census who have some form of caring responsibility. Most of these will not self-identify as a 'carer'
- Wakefield: 36,621
- Leeds: 71,598
- Calderdale: 21,369
- Kirklees: 43,665
- Bradford: 51,026
- Harrogate: 16,188

The value of carers across WY&H is approx. £4.5 billion per year, split as follows:
- Wakefield: Over £700 million
- Leeds: Over £1.3 billion
- Calderdale: Over £400 million
- Kirklees Over: £800 million
- Bradford Over: £900 million
- Harrogate Over: £300 million

Previous engagement with carers, carers' organisations and health and care professionals has highlighted a number of areas where as a system we can improve, this includes:
- Identification of carers
- Recognising the impact caring has on carer's health and well-being
- Carer awareness in primary and secondary care
- Developing innovative ways to signpost carers to information, advice and support
- Appointment and access to NHS services

- Information for carers regarding services available to them, recognising carers often do not have access to certain mechanisms of communication
- Carer awareness and culture within primary and secondary care recognising that there will be a number of our workforce within primary and secondary care that having caring responsibilities.

5.   Methodology

West Yorkshire and Harrogate Health and Care Partnership held a half day carers and primary care engagement event on Tuesday 25 September at Clayton Hotel Leeds in Leeds.

The event was supported by NHS England and focused on improving the quality of life and well-being of the 260,000 carers living across the area. The event also provided an opportunity for an open and honest conversation about the role of primary care in. The aim of the event was to;

- Build on work to date
- Agee how as a system we can improve the quality of life for carers
- Identify how leaders within the system can make it happen
- Agree some indicators which will demonstrate the impact if we get it right

This event was an essential part of our engagement process and included a range of health and care professional's working in primary care such as;

- GP Practices
- Social Care
- Community sector

It is important that we work in collaboration with all of our partners within the system and recognise the challenges in changing roles within health and social care, and particularly in primary care. This event will be another step to genuine and authentic conversations about how we can work together to support the work we are doing as a system.

Effective communication will build support for proposals and identify concerns. As a partnership we are committed to open and honest conversations to develop solutions together.

See appendix 2 for the event plan.

6.   Carers & primary care engagement event

Health and care professionals were invited by invitation (see Appendix 3) and through this invitation were asked to nominate representatives to attend the event. This was to ensure there was representation from across West Yorkshire and Harrogate.

6.1   Presentations

The event was delivered as part presentation and part discussion. The presentations were as follows:

- Welcome and introduction, and why are we here presented by Fatima Khan-Shah carers lead for West Yorkshire & Harrogate Health and Care Partnership
- Purpose of the day and why should primary care support cares presented by Dr Gordon Sinclair, Clinical Chair Leeds Clinical Commissioning Group
- NHS England's approach to supporting carers within primary and secondary care presented by Dave Ross, Leadership Support Manager for NHS England
- The West Yorkshire and Harrogate Partnership Carers Programme presented by the carers lead for West Yorkshire & Harrogate Health and Care Partnership
- Our vision for carers in Primary Care presented by Fatima Khan-Shah, Carers lead for West Yorkshire & Harrogate Health and Care Partnership and Dr Gordon Sinclair, Clinical Chair Leeds Clinical Commissioning Group
- So what happens next presented by Fatima Khan-Shah, Carers lead for West Yorkshire & Harrogate Health and Care Partnership

During the presentations there was also a film shown this can be found by visiting our website at the following link https://www.wyhpartnership.co.uk/our-priorities/unpaid-carers

The presentations used can be found by visiting our website here.

6.2   Gathering views

There were nine tables around the room with various health and care professionals from GP practices, social care and community organisations.

Following the presentations we asked participants as part of the table discussions to think about the following;

- How can we improve quality in these areas for carers together?
- How can we as leaders support this?
- How do we know it is working (or will work)?

Participants had an opportunity throughout the morning to be part of a table discussion. Flip chart paper was provided to capture table discussions and participants were also asked if they would like to write comments on a post it note as part of a facilitated table discussions.

An evaluation form (see appendix 4) also gathered people's views at the end of the event, and provided a final opportunity for participants to tell us anything they thought we should know.

Information provided in delegate packs was:
- Agenda
- Delegate list
- Speakers biographies
- The Carers strategy
- Quality care markers
- Evaluation form
- WY&H HCP publications
- NHS England publications
- Note Paper

The WY&H HCP communications and engagement team used twitter throughout the event providing quotes from guest speakers. Audience members also used twitter giving immediate feedback of the event. WY&H HCP Twitter address is @WYHpartnership.

A post event news feed can be found on our website at the following link https://www.wyhpartnership.co.uk/news-and-blog/news

The findings from the event are captured below and include all the feedback received from the table discussions and evaluation form.

7.   Findings from the event

7.1   Table discussions

The event took place on Tuesday 25 September 2018 at Clayton Hotel Leeds, City Walk, Sweet Street, Leeds LS11 9AT, with 46 people attending the event.

Findings from each of the table discussions and the evaluation form can be found below.

See section 9 for overall themes and key messages from this event.

We asked participants as part of table discussions to consider the following questions:

- How can we improve quality in these areas for carers together?
- How can we as leaders support this?
- How do we know it is working (or will work)?

Conversations were recorded on a data capture template (see appendix 5). The key themes from this feedback are below; for activity raw data see appendix 6.

Q1) How can we as a system improve quality in these areas for carers (the quality markers for GP practices)?

- Have champions in each GP practice
- Have mechanisms and system to identify and register someone as a carer
- Have leaflets, display boards TV adverts etc. to promote services that are available to carers
- Carers to receive a full carers assessment
- Explore the use of carers passports within the community
- Professionals need to understand what it is like to be a carer and the issues they face

Q2) How can we as leaders within the system support this?

- Professionals need to have knowledge and understanding of what services are available for carers and be able to signpost carers accordingly.
- There is a need to have the right leaders who are decision makers at the right meetings so they can influence and champion the right values
- Share information and learning
- Promote carers approach "Think Carers"
- Build good communication and working relationship between primary care, secondary care and voluntary care sector

Q3) How do we know if this is working (or will work)

- Review feedback in existing surveys e.g. the GP surveys
- Measure the experience of carers
- Use existing tools

Each table was invited to feedback their discussions so other people in the room were able to hear what other conversations had taken place; key themes from each table are below:

Table 1
- Ensure consistency
- Annual health checks and ask the right questions
- Learn and adapt

Table 2
- Understand the benefits of supporting carers
- Communicate effectively
- Have carer champions right across the system
- Use alternative resources such Healthwatch

Table 3
- Work in partnership with carers
- Utilise the carers register to identify carers
- CQC to incorporate carers into criteria this will promote positive competition

Table 4
- Come together as equal partners and talk to each other, understand each other's priorities
- Be able to deal with responses to questions
- Make the referral process simple
- Have a clear leadership plan to support the development
- Measure the experience of patient's staff and carers.

Table 5
- Introduce WebEx/e-learning and face to face training for all
- Have a consistent model
- Raise awareness of resources
- Share knowledge and good practice

Table 6
- Flag on system to identify carers
- Don't be afraid to ask difficult questions
- Train receptionists to increase the carers approach
- Have systems that talk to each other and share knowledge
- Recognise people as equals and not just carers
- Better sign posting to services
- Invest 'downstream'

Table 7
- Work at scale and do not rely on individual practices
- Introduce mandatory training and share policies
- Recognise the impact on education for young carers

Table 8
- Recognise the importance of professional awareness and improve understanding
- Encourage carers to talk more to their GP's
- Improve the registration process
- Join up mental and physical health services
- Support as leaders – make training mandatory
- Look at the side effects of medication and give information
- Improve confidence in how to sign post a carer
- Health professionals to communicate with each other

Table 9
- Look at what is on offer for carers, such as identification cards
- Share good practice
- Signpost to adult social care tool websites
- Raise confidence and understanding of the need for self-care
- Set quality markers

7.2   Evaluation

Each person who attended the event was asked if they could complete an evaluation form. Of the 46 people (approximately) 19 people completed or partially completed an evaluation form. Findings from the evaluation form can be found below; raw data can be found in appendix 7.

Presentations
Participants were asked to rate each presentation (including the content and presenter) and if the information was presented in a way that they could understand? By circling an appropriate number - 1 being no understanding at all and 10 being completely understand.

There were six presentations in total. The lowest score recorded was in relation to presentation three which scored 6 by two people. All other presentations scored 7 and above with the most prevalent scores being 9 and 10 equally. Participants said:

- The NHS England quality measures for carers are tricky to understand - it was challenging to understand fully from the presentation.
- Prior to the session we were given lots of information as facilitators/scribes about quality markers being voluntary - to counter GP critique - but I don't think this was the message we really want to take away about this initiative - people should want to evidence how they help carers!
- Shame about technology issues
- Didn't feel rushed, but also felt moving towards discussion work after the break
- Fast
- Excellent presentation. Very good variety of different professions
- I feel we needed social care in the room
- Interesting morning - very useful

- Really interesting and useful event. Lots of different perspectives from different people but all with the same aim
- More awareness at local level about the carers programme

Activity

Participants were asked to rate each activity (including the facilitators) and if they felt they were able to fully contribute, tell us everything they wanted to and felt that they had been listened to? By circling an appropriate number - 1 being no not at all and
10 being yes completely.

Apart from one person who didn't score this section all scored the activity as 8 and above with 10 being the most prevalent rating. Comments made:

- Feedback went on too long - perhaps choose top thing to each question
- Great interaction by all and good facilitation
- Table talk was good

From the 19 completed evaluation forms, the majority of delegates rated the registration, welcome and venue as very good.

People were also asked if there is anything else they would like to tell us; participants commented:

- Parent carers often caring for disabled children and elderly parents too DOUBLE CARING RESPONSIBILITY
- Enjoyed the day. Looking forward to change
- Overall good event, well facilitated
- Packs were very helpful
- Great event. Thank you for including us
- Several presentations would have benefited from venue / host preparation

Participants were asked to provide any other general comments and the following were given:

- Well organised event. Very informative information. I learnt about the primary care quality markers, annual healthcare checks for carers. Thank you
- Really well organised event with great pace and right balance. Well done to all involved ☺
- As a carer I would like to have seen the event being presented in partnership with carers. (Co-hosting, presenting etc.)
- Very good and informative
- Good to hear from carers as well as professionals
- Excellent. Thank you
- Feedback gets boring when people describe everything discussed - we could have had another 10 minutes valuable discussion
- Good event and networking on the topic
- Further detail on the offer from carer services and open conversation on where they need to improve would increase collaboration with primary care / PCH

8.   Equality

A total of 46 people attended the stakeholder event. Of those 12 people completed or partially completed an equality monitoring form (see appendix 8), representing 26% of attendees.

Participants were from Leeds, Wakefield, Bradford and Huddersfield with an age range from 26 to 56 with 92% being female.

The majority of delegates stated their country of birth as being UK/England with one person not providing this information.

With the exception of one person who described their ethnic group as Indian all other stated their ethnic group as White English/Welsh/Sottish/Northern Irish/British. One person stated their religion as Hinduism, three people quoted no religion and the remainder were cited as Christianity.

One person described themselves as having a disability which was sensory impartment with the reminder saying they did not consider themselves to have a disability.

Of the 12 completed forms 4 people confirmed they were carers.

1 person is pregnant with no-one giving birth within the last six months.

On the question of sexual orientation the majority stated Heterosexual/ straight (opposite sex), one person put Bisexual (both sexes) and one person preferred not to say.

One person described themselves as transgender, one person preferred not to say and the reminder said they were not transgender.

Raw data can be found in appendix 9.

9.   Overall findings and key messages

Key messages from the unpaid carers' event are summarised below.

Overall people supported the primary care quality markers and felt this would be an improvement to services carers receive by their GP practices.

Unpaid carers are a considerable resource to the NHS and their health and wellbeing is paramount to ensure they can continue in their caring roles. As such is vital to ensure carers are identified to prevent and delay carer 'burn-out' and/or 'breakdown' which results in both the cared-for person and the carer accessing and becoming dependent on formal health and care services.

There is an appetite for organisations to have a Carers Champion to help raise awareness and profile of carers, ensuring they are not forgotten.

It was felt staff including receptionists and health care professionals need to have appropriate training to be able to effectively identify carers, be able to handle difficult situations and have empathy for carers. They also need to have the resources and

confidence to efficiently and appropriately sign post carers appropriately to other service, including third sector organisations.

10. How the findings will be used

This report of findings will be reviewed by the carers project group who will consider next steps, ensuring the carers voice continue to be listened to within West Yorkshire and Harrogate Health and Care Partnership.

The report will be shared with those who attended the event and people who have previously expressed and interest the carers work. The report will also be uploaded to the West Yorkshire & Harrogate Health and Care Partnership website.

Appendix 1 – Key drivers and legal obligations

Health and Social Care Act 2012

The Health and Social Care Act 2012 makes provision for Clinical Commissioning Groups (CCGs) to establish appropriate collaborative arrangements with other CCGs, local authorities and other partners. It also places a specific duty on CCGs to ensure health services are provided in a way which promotes the NHS Constitution – and to promote awareness of the NHS Constitution.

Specifically, CCGs must involve and consult patients and the public:

- In their planning of commissioning arrangements
- In the development and consideration of proposals for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
- In decisions affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact

The Act also updates section 244 of the consolidated NHS Act 2006 which requires NHS organisations to consult relevant Overview and Scrutiny Committees (OSCs) on any proposals for a substantial development of the health service in the area of the local authority, or a substantial variation in the provision of services.

The Equality Act 2010

The Equality Act 2010 unifies and extends previous equality legislation. Nine characteristics are protected by the Act: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion and belief; sex; and sexual orientation. Section 149 of the Equality Act 2010 states all public authorities must have due regard to the need to a) eliminate discrimination, harassment and victimisation, b) advance 'equality of opportunity', and c) foster good relations. All public authorities have this duty and will need to be assured that "due regard" has been paid.

The NHS Constitution

The NHS Constitution came into force in January 2010 following the Health Act 2009. The constitution places a statutory duty on NHS bodies and explains a number of patient rights which are a legal entitlement protected by law. One of these rights is the right to be involved directly or through representatives:

- In the planning of healthcare services
- The development and consideration of proposals for changes in the way those services are provided
- In the decisions to be made affecting the operation of those services

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1. Purpose of the plan

The purpose of this plan is to describe how we will deliver the carers and primary care event which aims to provide an opportunity for an open and honest conversation about the role of primary care in:

- Improving the quality of life and health and well-being of carers
- Preventing and delaying carer 'burn-out' and/or 'breakdown' which results in both the cared-for person and the carer accessing and becoming dependent on formal health and care services

This plan will include;
- Background
- An overview of the event including the purpose and delegates
- Objectives of the event and the proposed agenda
- Communications
- Presenters, facilitators and venue and Invite

2. Background

West Yorkshire & Harrogate Health and Care Partnership (WY&H HCP) have been recognised by NHS England as an exemplar site for developing support for unpaid carers. There is an overarching project team who are working with NHS England to establish a transformational approach to carers support.

We estimate that there are around 260,000 unpaid carers in West Yorkshire and Harrogate. As public services continue to face financial pressures, increasing demand, the introductions of new legislation and approaches, and changing expectations of citizens, increasing numbers of unpaid carers are taking on responsibility for more intensive levels of care. This combined with changes in retirement age, means the demographic of unpaid carers across the country is changing too. This will become more complex as the changes in retirement age means people will be working until much later than is currently the case and therefore juggling work and caring for longer.

Although caring can be rewarding, there is substantial evidence that carers have poorer physical and mental health than those who are not caring, and that the more care you provide the more likely you are to have poorer health. For many carers, the biggest priority is the health and wellbeing of those they care for and as such they are more likely to neglect their own health and are known to put off treatment for themselves.

As a partnership we recognise that carers play a significant role in delivering and supporting health and care and that without them the health and care system would be overwhelmed. Carers are recognised in a number of partnership work-streams and our next steps document. We want to raise their profile and share the excellent work taking place across the area.

In addition we also want to celebrate the difference this is making in our communities on a regional and national level – and most importantly ensure that this is applied for all carers no matter where they live in West Yorkshire and Harrogate.

While most carers are not known, for example to social care services, an estimated 90% access a primary care service either visiting with the person they care for and/or for themselves. This means that primary care services are ideally placed to identify carers, to register them and to link them to the information and support that is available locally.

Early identification and support through contact with primary care can enable carers to cope better to ensure their own health does not deteriorate which in turn means they are more able to continue in their role as partners in patient care.

However, a failure to support carers effectively is likely to result in a deterioration of their health meaning they are less likely to be able to continue caring and more likely to present as unwell in a GP surgery.

Our vision is to support primary care services to identify carers routinely and to signpost them to relevant information, advice and support.

Previous engagement with carers, carers' organisations and health and care professionals has highlighted a number of areas where as a system we can improve. These include:

- Identification of carers
- Recognising the impact caring has on carer's health and well-being
- Carer awareness in primary and secondary care
- Developing innovative ways to signpost carers to information, advice and support
- Appointments and access to NHS services
- Information for carers regarding services available to them recognising that carers often do not have access to the normal mechanisms of communication to do their caring roles
- Carer awareness and culture within primary and secondary care recognising that there will be a number of our workforce within primary and secondary care have caring responsibilities.

3. Overview of the event

The workshop will start at 9:30 am until 12:30 pm and will be held in Leeds at the Clayton Hotel. Registration will be from 9:00am until 9:30am.

The event will ensure that we have appropriately engaged, properly discussed, listened to and considered all comments from stakeholders.

The purpose of the event is to ensure every effort is made to engage and increase awareness of the role of carers within the West Yorkshire and Harrogate Health and Care Partnership. This will help to ensure support for carers is given the recognition and profile it deserves within all the work streams of the partnership.

It is important that we work in collaboration with all of our partners within the system and recognise the challenges in changing roles within health and social care, and particularly in primary care. This event will be another step to genuine and authentic conversations about how we can work together support the work we are doing as a system.

Effective communication will build support for proposals and identify concerns. As a partnership we are committed to open and honest conversations to develop solutions together.

All stakeholders will invited by invitation (see Appendix 1).

This event is an essential part of our process where we will demonstrate that we have taken the time to fully consider the views of stakeholders.

3.1 Delegates

The stakeholder list is under development and is an essential part of our commitment to engage with all sectors and ensuring the stakeholder list is fully representative. A range of stakeholders will include:

- Clinical Chairs
- Primary Care GPs,
- Practice nurses,
- Primary Care Commissioning Committee chairs
- Directors of adult and children services from local authorities.
- Primary Care Federations
- Community Primary Care Providers
- Secondary care representatives

4. Objectives of the workshop

The objectives of the event are:

- Ensure there is a consistent approach across West Yorkshire and Harrogate to routinely identify carers, and signpost them to local and national information, advice and support services
- Work in collaboration with NHS England to develop quality indicators for carers in primary care
- Support John's campaign with primary care, encourage carers to remain during consultations of patients living with dementia.
- Prevent and delay carer 'burn-out' and/or 'breakdown' which results in both the cared-for person and the carer accessing and becoming dependent on formal health and care services

**West Yorkshire and Harrogate
Health and Care Partnership**

AGENDA – Primary Care Carers Workshop
Tuesday 25 September 2018 from 9am – 12:30pm
Clayton Hotel, Sweet Street, City Walk, Leeds, LS11 9AT

Time	Activity
09:00 – 09:30	Registration / refreshments on arrival
09:30 – 09:40	Welcome
09:40 – 09:50	Purpose of the day – Why should primary care support carers?
09:50 – 10:10	A Carer's Story – Why it is important to support carers within primary care
10:10 – 10:30	NHS England's approach to supporting carers within primary and secondary care
10:30 – 10:45	West Yorkshire & Harrogate Carers Programme
	Comfort break / refreshments
11:00 – 11:05	Our Vision for Carers in Primary Care
11:05 – 11:30	Table Discussions
11:30 – 12:15	Feedback and next steps
12:15 – 12:30	West Yorkshire & Harrogate Cancer Alliance - Cancer Care Review Listen & Design Event
	Thank you & Close

5. Communications

The communications required prior to and after the event are set out below. The development of these materials will be led by the communication and engagement team as part of a planned approach to delivering the event.

The lead facilitator will provide a briefing to table facilitators and scribes before the start of event.

Pre event activity:

- To identify interested stakeholders
- To develop an invitation
- To co-ordinate the development of presentation material
- Develop discussion material and mechanisms to capture discussions
- Develop signing in sheets
- Social media
- Prepare a delegate pack that will consist of:
    - Content list of what is in the pack
    - Agenda
    - Delegate list
    - Biographies
    - Presentations
    - Who's in the room
    - The Carers Strategy
    - Evaluation Form
    - Equality Monitoring form
    - WY&H HCP publications
    - NHS England publications

Post event activity:

- To type up all notes and flip charts
- Analyse the event discussions
- Oversee the production of the event report
- Feedback the findings to participants with a covering letter to thank them for participating
- Feedback the findings to other stakeholders who have expressed an interest
- Publish the event report on the Partnerships' website
- Social media

6. Presenters, facilitators and venue

The communications and engagement team will be responsible for the overall development of the presentation material.

Presentations required on the day:

- Welcome – Carers Programme Lead
- Purpose of the day – Carers Programme Lead
- A Carer's Story – Why it is important to support carers within primary care - Carers Programme Lead
- NHS England's approach to supporting carers within primary and secondary care - Leadership Support Manager
- West Yorkshire and Harrogate Carers Programme – Carers Programme Lead
- Our vision for carers in Primary Care – Carers Programme Lead
- Table Discussions
    - How can we as a system improve quality in these areas for careers
    - How can we as leaders within the system support this
    - How do we know if this is working
- Feedback and next steps – Carers Programme Lead
- Caner Care Review Listen & Design Event – Project Officer

Presenters

There will be two presenters who will convey information to the delegates and engage in a question and answer session.

Facilitators and scribes:

Each table will have a facilitator and a scribe.

Table facilitator: Is responsible for engaging all people around the table to openly and honestly talk around the given subject. The facilitators will feedback to the whole room summarising key points and themes from the table discussions.

Table scribe: Is responsible for capturing all conversations around the table by making extensive notes. The notes will be typed up after the event and will be used to inform key messages and any themes and trends.

Scribes will collect their tables' material including the notes they have captured and be responsible for typing up their notes and sending them to the communication and engagement team.

Workshop facilitator: The event will be chaired by the carers programme lead who will manage the agenda, present house-keeping, introduce each presenter and the activities. The event facilitator will also provide the verbal brief on the morning of the event.

Venue management: The communications and engagement team will lead and manage the event which will include setting up the venue, providing AV and a roaming mike, managing up load of presentations and room set up, registration, packing up and transporting equipment and collateral.

Room layout: the room layout will be cabaret style and we anticipate up to 80 attendees for the event.

Refreshments: We will provide refreshments on arrival and during the break.

7. Budget

The stakeholder event will be funded from NHS England. The resources and budget required are listed below:

Primary Care Marker - Carers Event: Budget	
Item	**Estimated Cost**
Venue Hire – NHS England to cover this cost	**£0**
Refreshments and lunch – NHS England to cover this cost	**£0**
Equipment hire – PA system, projector – NHS England to cover this cost	**£0**
Travel and subsistence and out of pocket expenses – if requested	**£200 est.**
Interpreter costs/BSL if requested	**£500 est.**
Printing costs	**In house**
Estimated TOTAL	**TBC**

**West Yorkshire and Harrogate Health and Care Partnership
Carers & Primary Care: Engagement Event
Date: Tuesday 25 September
Venue: Clayton Hotel Leeds, City Walk, Sweet Street, Leeds LS11 9AT**

West Yorkshire and Harrogate Health and Care Partnership would like to invite you to attend a ½ day carers and primary carer's engagement event. Please confirm your attendance by Monday 10 September 2018 by completing the attached registration form and returning it by email to Joanne.Rothery@wakefieldccg.nhs.uk or by calling 01924 317659. If you are unable to attend, please nominate a representative. Please also find attached agenda for the day, map and directions and information on parking.

>>>

The event is supported by NHS England and will aim to provide an opportunity for an open and honest conversation about the role of primary care in improving the quality of life and health and well-being of carers. And preventing and delaying carer 'burn-out' and/or 'breakdown' which results in both the cared-for person and the carer accessing and becoming dependent on formal health and care services. This event aims to bring together a wide range of people from across primary care such as GPs, primary care and community staff, commissioners, voluntary and community sector, Healthwatch and carers.

Guest speakers will include Jen Kenward, Experience of Care Lead – Community, Primary & Integrated Care, NHS England, Dr Gordon Sinclair Clinical Lead of Leeds Clinical Commissioning Group and Fatima Khan Shah, programme lead, will host the event alongside national guest speakers, including David Ross NHS England Patient Experience Team.

Further information

West Yorkshire & Harrogate Health and Care Partnership have been recognised by NHS England as an exemplar site for developing support for unpaid carers. There is an overarching project team who are working with NHS England to establish a transformational approach to carers support.

We estimate that there are around 260,000 unpaid carers in West Yorkshire and Harrogate. As public services continue to face financial pressures, increasing demand, the introductions of new legislation and approaches, and changing expectations of citizens, increasing numbers of unpaid carers are taking on responsibility for more intensive levels of care. This combined with changes in retirement age, means the demographic of unpaid carers across the country is changing too. This will become more complex as the changes in retirement age means people will be working until much later than is currently the case and therefore juggling work and caring for longer.

Although caring can be rewarding, there is substantial evidence that carers have poorer physical and mental health than those who are not caring, and that the more care you provide the more likely you are to have poorer health. For many carers, the biggest

priority is the health and wellbeing of those they care for and as such they are more likely to neglect their own health and are known to put off treatment for themselves.

As a partnership we recognise that carers play a significant role in delivering and supporting health and care and that without them the health and care system would be overwhelmed. Carers are recognised in a number of partnership work-streams and our next steps document. We want to raise their profile and share the excellent work taking place across the area.

In addition we also want to celebrate the difference this is making in our communities on a regional and national level – and most importantly ensure that this is applied for all carers no matter where they live in West Yorkshire and Harrogate.

Jill Dufton | Engagement Manager
West Yorkshire & Harrogate Health and Care Partnership (WY&H HCP)
NHS Calderdale & Greater Huddersfield Clinical Commissioning Groups (CCGs)
Mobile 07554414879
Email jill.dufton@calderdaleccg.nhs.uk

www.wyhpartnership.co.uk | @wyhpartnership

Appendix 2 – Registration Form

WY&H HCP Carers & Primary Care: Engagement Event - Registration Form **Date:** Tuesday 25 September 2018 **Time:** 9:30 - 12:30 (9:00 – 9:30 registration) **Venue:** Clayton Hotel Leeds, City Walk, Sweet Street, Leeds LS11 9AT	
Please complete this form to register for the event and return to via email to **Joanne.Rothery@wakefieldccg.nhs.uk** **Please return this form by Monday 10 September** If you need have any questions about the form please email us on**:** **Joanne.Rothery@wakefieldccg.nhs.uk**	

1. Please tell us who will be attending the event:	
Name	
Email or telephone number	
If more than one person attending please provide their name and contact details here:	

2. Are you attending as:	
an individual ☐	on behalf of an organisation or group ☐
If attending on behalf of an organisation or group please tell us which one:	

3. Please can you tell us if you have any dietary requirements (for example: gluten free, dairy free, vegan, vegetarian, halal, kosher etc.)

4. We aim to ensure that people have equal access to public events. **If you need additional support such as alternative formats or other reasonable adjustments please tell us. (For example: documents in alternative formats such as: large print, easy read, braille**

West Yorkshire and Harrogate Health and Care Partnership
Carers & Primary Care: Engagement Event
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Time: 9:30 - 12:30 (9:00 – 9:30 registration)
Venue: Clayton Hotel Leeds, City Walk, Sweet Street, Leeds LS11 9AT

Please complete this form to register for the event and return to via email to
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If you need have any questions about the form please email us on**:**
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1. Please tell us who will be attending the event:

Name	
Email or telephone number	
If more than one person attending please provide their name and contact details here:	

2. Are you attending as:

an individual	☐	on behalf of an organisation or group	☐
If attending on behalf of an organisation or group please tell us which one:			

3. Please can you tell us if you have any dietary requirements (for example: gluten free, dairy free, vegan, vegetarian, halal, kosher etc.)

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**West Yorkshire and Harrogate
Health and Care Partnership**

Feedback
Co-production event for the
West Yorkshire and Harrogate Health Care Partnership (WY&H HCP)
Tuesday 25 September 2018 9.00am to 12:30pm
The Clayton Hotel, Leeds

Name & Organisation (Optional) ....

Presentations (including content and presenter) – Was the information presented in a way that you could understand?	Please rate by circling the appropriate number - 1 being no understanding at all and 10 being completely understand
Presentation 1 – Welcome and Introductions	1 2 3 4 5 6 7 8 9 10
Presentation 2 – The purpose of the day – Why should primary care support carers?	1 2 3 4 5 6 7 8 9 10
Presentation 3 – NHS England's approach to supporting carers within primary and secondary care	1 2 3 4 5 6 7 8 9 10
Presentation 4 – The West Yorkshire and Harrogate Partnership Carers Programme	1 2 3 4 5 6 7 8 9 10
Presentation 5 – Our vision for carers in Primary Care	1 2 3 4 5 6 7 8 9 10
Presentation 6 – So what happens next	1 2 3 4 5 6 7 8 9 10
Is there anything else you would like to tell us?	

Activities (including facilitators) – were you able to contribute fully, tell us everything you wanted to and feel that you where listened to?	Please rate by circling the appropriate number - 1 being no not at all and 10 being yes completely
Activity 1 – Group work in themed	1 2 3 4 5 6 7 8 9 10

discussions				
Is there anything else you would like to tell us?				31
Please rate the following by ticking the appropriate box	**Very good**	**Good**	**Poor**	**Very Poor**
Registration				
Welcome				
Venue				
Is there anything else you would like to tell us?				
Any other general comments?				
Thank you for taking the time to complete this form				

Appendix 5 – Data capture form

West Yorkshire and Harrogate
Health and Care Partnership

Date	25 September 2018
Venue	Clayton Hotel Leeds, City Walk, Sweet Street, Leeds, LS11 9AT
Event	Primary Care Carers Workshop
Time	Facilitators Scribes arrive for 8:30am Event 9:00am – 12:30pm
No. of people on table	8
Table Number	PLEASE ADD TABLE NUMBER
Table Facilitator	PLEASE ADD NAME
Scribe	PLEASE ADD NAME

Instructions:

- This template is used to report key outcomes in a standard way, the table scribe is responsible for taking notes on the day, either directly into this template or by transposing their notes into this format later. If you are using this to record points on the day please expand the boxes to allow for notes.

- Note taking should focus on summary points and agreements rather than providing a verbatim transcription – please follow the above reporting note to record the expressed sentiment to allow for

- The role of the table facilitator is to keep the discussions 'on task' and to move the discussions on if it becomes stuck on one point or the discussion is being dominated by one (or two) individuals. Encourage quieter members to contribute by asking them directly for their opinion, but do not push if they do not wish to participate.

- For those who are not keen to participate – remind participants they can complete the evaluation form or write comments on a post it note

Question 1
How can we as a system improve quality in these areas for careers

Question 2
How can we as leaders within the system support this

Question 3
How do we know if this is working

Appendix 6 - Event activity raw data

Date	25 September 2018
Venue	Clayton Hotel Leeds, City Walk, Sweet Street, Leeds, LS11 9AT
Event	Primary Care Carers Workshop
Time	Facilitators Scribes arrive for 8:30am Event 9:00am – 12:30pm
No. of people on table	8
Table Number	PLEASE ADD TABLE NUMBER
Table Facilitator	PLEASE ADD NAME
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- For those who are not keen to participate – remind participants they can complete the evaluation form or write comments on a post it note

Question 1
How can we as a system improve quality in these areas for careers

---

Table 1

Speak to carers - talk to carers together. We don't get to hear all of their voices.

They aren't asked to contribute as a carer to surveys etc.

Identification – caring is transitional, it's a journey and people identify themselves differently along the path. We do need a register.

- GPs should look at patients with dementia, stroke etc. and see who is around them doing the caring.

- Look at their circumstances.

- It is the responsibility of the whole practice team – they should all be able to identify carers and signpost to help. Staff may need training.

- The yellow card scheme is good – help the carer to identify themselves. Ensure there are leaflets and posters in appropriate places.

People asked "so what?" What difference would identifying them make?

There was a suggestion that having carers groups in practice would be good. People already know the venue and could find support from neighbors etc. Hold coffee mornings, with or without patient.

Holistic support – Ask open questions, where are you now? What would help?

- Start with the carer, where they are comfortable and when. This could be a weekend or evening if it was a young carer or in school.

- Support their needs.

In-practice support – a Champion in all practices v all practice staff being champions. Yes, one person needs to have leadership and provide drive, share learning, access tools. This should include pharmacies too, all taking responsibility.

Computer help – some people who cared said how useful this was to help with prescriptions appointments etc. However, other people felt that it could make people more lonely and that identification of carers would be difficult if they are not seen face to face.

How are we communicating e.g. with young carers – social media?

Appointments – Have to make these convenient

- It would be good to see the carer (for whatever need they have) whilst seeing the patient. This would save both the carer and professional from bureaucracy of making a separate appointment and the time involved.

People felt that the Annual Health Check for carers was not enough, although it was accepted that it was proactive and a safety net for people. Care should be ongoing. This relationship is needed to build trust.

Table 2

- Carers need help in understanding benefits and how to access them – a range of contact methods should be available, always including face-to-face
- Models of good practice cited included the one stop shop at Pudsey general practice, and also Bradford and Airedale, where the Citizens Advice Bureau comes out to the GP surgery; Making Space, family support in secondary care, Healthwatch Wakefield and Bradford
- Health professionals don't automatically refer carers to people and services who can help them.
- They should always 'THINK CARER' in everything they do
- Remember – finances may be an issue for carers, and may impact on everything they do, how you contact them, how they use services (e.g. having to hang on the phone if they use a pay as you go mobile)
- Some discussions about what could happen in GP practices to make life easier/better for carers:
  - i) Ensure it is clearly shown on a carer's notes that they undertake that role so it cannot be missed
  - ii) Practice level carers groups
  - iii) Gap analysis at practice level
  - iv) A better understanding by the GPs themselves about what's available in the area to which patients/carers could be signposted
  - v) Each practice to have a GP champion for carers
  - vi) Introduction of care navigation could help
  - vii) Leaflets on the counter promoting services for carers
  - viii) Recognition that the carer may be registered at a different practice to the person they are caring for
  - ix) Ensure co-production with carers

- Consideration should be given to the impact/role of 'hidden carers' who are providing support to patients and carers, probably without realizing it, e.g.
  - Pharmacy delivery drivers
  - Utilities meter readers
  - Delivery drivers, couriers

All coming into contact at home and may be providing some degree of support, contact etc.

Table 3

- Practices should work in partnership with carers to get a better understanding
- Training should take on a whole practice approach and be carer aware
- Work with staff that have carer experience and have key 'carers champions' and better sign post the carers leads
- Involve the whole team as this is the responsibility of all staff
- Use annual health checks for carers as an opportunity for carers to reach out. Not everybody has a clinical need they may just need to talk to someone.
- It's difficult to maintain momentum alone it is better to get people sat around a table
- Practices need to realise and identify the number of patients who are carers

Table 4

- Come together as equal partners and talk to each other – understand each other's priorities. All working smarter together.
- Explore how we can be mindful of carers. It's very hard to put their needs above others. – Don't put above but raise awareness.
- Educate people in this area so they know the right questions to ask. Be able to deal with the responses to questions – what action would a receptionist take if someone says they are not coping.
- Make the referral process simple. When the need is identified create an environment to enable all staff to deal with these situations.
- Some practices use the practice nurse to triage appointments.
- Create a system where smaller parts of the system are represented in a local group (e.g. Rob Arndel - local care partnerships in Leeds and patient partners) Helps for seeking and sharing ideas. Practices do not have to act in isolation. This means a system captures the knowledge and front line staff knows people.

- Create a clear process in the practice to refer issues in a systemised way and not in an ad-hoc way to make the best use of resources – e.g. volunteers in practices – can this be embedded into the clinical systems? Whilst adhering to confidentiality etc.

Table 5

- Share and develop 'top ten tips' about improving quality /experience. Tips on how to improve the outcome for patients should also be shared. Ten tips on what to do and how to do it would be useful for both carers and practices. Share information about carer services, identifying the number of carers who have been referred to carers services and identify the level of services needed. This insight can be used to develop services and improve experience.
- Choice should be built into the service process.
- Revisit the 'Triangle of care' as part of the process and be clear how this can be implemented practically.
- We need to widen the narrative; the GP role has been communicated but what about the pharmacies, voluntary sector role etc.
- Are the areas co-produced? If so we need to make sure this is communicated as such.
- Ensure Equality & Diversity issues are addressed as they are being identified.

Table 6

- There is no magic wand and there is a varied impact depending upon the level of buy-in from GP practices.
- Carers coffee morning/carers chats that are well attended can be used to provide information service views, communicate
- We need to think about how we deal with the emotions around being identified as a carer.
- Get people to identify as carers and manage that process sensitively and identify this as a positive. More of this needs to be done at receptionist level, such as flagging a person as a carer which can act as a trigger for a slightly different conversation. GP's cannot be the full answer which is the public perception.
- Refer to carers organisations as colleagues; this will help them to be seen as a credible alternative part of the system.

- There needs to be a more prescriptive approach rather than carers getting to crisis point before getting support.
- Train receptionists and get carers organisations involved in the delivery of the training on awareness of early detection of changes in how someone is presenting themselves.
- Active sign posting to be included in the care register
- Offer digital resource for carers as a means of delivering training across areas

Dispelling myths around caring:

> - I can't get help because I am working
> - I'm not a carer, I'm a wife this is what I signed up for
> - It's not bad enough for me to be able to access support

- Can you get proxy access to online records for things such as ordering prescriptions etc. if you are not from the same practice?
- What happens if carers and patients with different GP practices need support? For example a carer maybe unwell but are attending an appointment for the person they are being cared for? There is an importance to ask the carer how they are, not just the person they care for.
- Wellbeing assessments for carers using welcoming and supportive language
- Make double appointments available for carers if they require them.

Table 7
- Provider partnership role: experiences of carers shared
- Accommodate support in primary care which isn't just clinical
- Different sectors around a table approach to look at system identification of carers, capturing unidentified carers through assessments
- Having carer(s) part of the team that are assessing
- Within secondary care, it is often assumed that carers are identified within primary care, we need to change this way of thinking too
- Primary care networks involve a lot of systems, how can we reach out to the wider system
- Identification and registration needs to be an integrated system
- Community partnership – Wharfedale has been recognised as the place which holds records of carers and therefore in-theory this should follow the person. They also sign posting carers and capture feedback

- Engagement from stroke programme, has led to the identification of carers and sign posting process but there is still a lot to be done
- Number of different services can potentially be too much and overwhelming for carers
- There are 'trusted assessments' no matter what the condition
- 'Social prescribing' enables communication and simplicity; in practice this needs to be shaped into ICS approach
- Principles of safe guarding, compliance within the system and potentially having a similar training setup will allow for a greater system approach
- We need to look to raise the profile, in terms of parity of esteem
- Biggest challenge is that GP practices will do what they feel is appropriate for them – culture change
- Utilisation of services to help carers cope better
- Homes with carer support
- Carers to be part of those loved-ones conversations to ensure clarity and taking information on-board
- Clear carer navigation through the system
- Quality assurance visits = better community support
- Patient health records, enabling people to identify themselves as carers

Table 8
- Raise professional awareness around their understanding of what it is like to be a carer. They also need to be aware and understand the quality markers.
- Have more carer champions on wards – although recognise that this does already happen in some places.
- A good point to recognise if someone is a carer is when signing up and accessing GP practices. Ask the question "do you see yourself as a carer" People can respond as they choose. Need to recognise a carer can become a carer overnight which is why this questions should not be restricted to just being asked on registration. 6000 people a week become carers.
- Also need to help people understand what a carer is.
- Get people with carer experience to talk to professionals about their experiences and explain what it's like for them.
- People/carers should be asked "Do you want to be a carer or are they happy to

carry on being a carer".

- Carers should be given a full carer assessment, which they are entitled to.
- Make every contact count.
- There is a big gap between mental and physical disabilities for carers.
- A therapist worked with a carers group in Wakefield who meet at a GP practice which is very successful.
- It can take a long time for people to get into a service and services are often not joined up – this needs to improve.

Table 9

- Does quality begin with identification? We agreed that it did.
- Improved quality starts with a robust mechanism for identifying and registering carers. An example of this is the Leeds Care Record (Pudsey) where a flag to identify frailty is used. Could a similar system be used to indicate the person is a carer both in secondary and primary care patient record systems?
- Would such a system help when a person presents in A&E departments. System access to information which identifies carers is more difficult following GDPR regulations.
- Explore the use of 'identification cards' such as those used by patients with LTC.

Need to address the stigma attached be being a carer:

  - Asking patients which ways could be used to help to identify carers

  - Display boards/TV adverts about what carers are and the support available in GP practices

  - LTC registers – what information is held which may help identify carers

- Bradford Social care work with Bernardo's to identify young carers. They also have a strong relationship with school nursing services
- In Harrogate social care is working with schools to identify young carers
- Identification is a bigger issue in some areas such as mental health and alcohol and substance misuse, often involving young carers.
- Other suggestions (some proven to work) are the use of campaigns such as the Flu Vaccination clinics when people are brought by somebody – opportunistic identification of carers.
- Need to explore the use of Carers Passports as developed by Carers Trust and

Carers UK

- There is a need to empower carers to come forward and to be more open about the restrictions the caring role places on them when arranging and attending appointments in primary and secondary care. Equally primary and secondary care needs to be more aware of the potential issues for patients with caring responsibilities. Need to upskill staff.
- It is important that registers for carers are well maintained as a carers circumstances may change if the person being cared for no longer requires care (if person dies – caring responsibility may cease).

Question 2

How can we as leaders within the system support this

Table 1

- Aim for consistency across the patch.
- Share tools
- Support for practices who want to do more.
- Look at people/communities who already suffer inequalities e.g. South Asian women – they will be doubly impacted.
- Support the voluntary, community and faith sector. They can provide support – could they do this in the practice?
- Improve ways for people to access social care before there are in crisis. This is difficult as people think they are wasting services if they access them too early and also feel it will upset loved ones.
- Need to work on multi-agency approach.
- Support at Federation/network etc. level (Community partnerships – Bradford, Local Care partnerships – Leeds)

Table 2

- We can all act as champions for carers.

- We can all use our professional skills to support carers in different ways

- Keep the conversation going – THINK CARER!

- Ensure we appreciate that the work of primary care is wider than just GPs

- As professionals, we ALL need to have a good understanding and appreciation of what is out there for carers, so we can signpost as and when we may need to

- Encourage people to look at good practice, e.g. John's Campaign

- Ensure that any messages we put out that are targeted at the caring community are actually relevant to and clearly understood by them

- Carer stories need to be built into key meetings, such as Board meetings, so there is a constant reminder of the challenges they face

- Whole organisations need to be 'carer friendly' – having clear policies and procedures in place aren't enough on their own, compliance through the behavior and commitment of each individual is what will make the difference. So….

  Carer stories at Board level

  Policies and procedures in place

  Appropriate training for all staff

  Ensure all behaviors reflect a commitment to and understanding of carer issues – e.g. flexibility with appointment times offered

Being open to feedback on how they are doing and being willing to change as a result of that feedback

Table 3
- Everyone wants good ratings; incorporating the carers area into the CQC visits would be positive and it could be used as a way to promote a new way of doing things.
- As leaders we need to be aware of what is real at the time as carers needs change daily. There needs to be a flexible approach
- 'Think differently and be different'.
- It is our responsibility to think about the bigger picture and how it will affect the carer.
- Be mindful and do not be afraid to ask questions.

- Share good practice
- Look at the benefits of locality working
- Build partnerships between Mental Health services and GP's.
- GP practices need to be aware that it could take a carer a long time to realise they need help they do not want to be questioned by a receptionist.
- Realise the benefits of locality working.

Table 4

- Do some communication with practices to raise their awareness of the markers.
- Promote carer organisations when training staff.
- We need the right leaders within the different organisations to be involved in the meetings – decision makers.
- Provide longer term funding to ensure consistency of services and trust people to do this.
- Look longer term. Losing money from acute to primary care may benefit the acute in the long term. Look long term not short term.
- Work together as equal partners.
- Have a clear leadership plan to support the development of great leaders who will champion the right values, competencies and ultimately influence the normalising of the standards.
- Train volunteers as well as staff and value their contribution and expertise.

Table 5

- Share information in an easy to understand format.
- GP's need to have the knowledge and understand the services the voluntary sector have.
- Good practice from other regions/geographical areas should be shared.
- Develop a peer to peer approach; this process should be optional so we need to look as how more GP practices can sign up to this.

Example shared:
  - ❖ Peer to peer sharing of information learning, challenges benefits, etc. between GP's who opt in and those thinking about doing so.
  - ❖ Produce a fact sheet detailing expectations, top tips etc.
- Discuss how the system can flag carers and carers can be identified.

- Use simple language avoiding jargon and acronyms.
- Communicate differences made and close the loop with those who have provided feedback
- As leaders we need to take ownership and use leverage with bodies such as CQC, etc.

Table 6
- We need to drip feed carers into our conscious 'Think carer'
- Involve the CQC to incentivise practices to engage with carers services.
- Bring out the competitive nature of GP's – quality markers, measurable's must be genuine
- In an integrated system carers support services and cares should be seen as equal with clinical professionals and be referred to as a colleague. Make sure carers are an embedded part of the new primary care networks

Table 7
- "thinkcarers!" – we need to promote the carers approach
- Joined up working in primary and secondary care
- Software which links and has carers within systems; is there anything we can do to integrate systems?
- Difficulty in creating a new system; but a new system approach would benefit the carer and patient
- Primary care carer video by Leeds has a good narrative, looking at how they created an approach, dependent on leadership in-put
- Case for change = looking at demographics; increasing expectations on who is going to care for people; communities with different needs and health priorities; social health challenges
- Crete the right circumstances e.g. leadership / 3rd sector support / create the narrative
- Upscaling how services are preforming; are they registering carers; find out what carers needs are and reduce the need to re-visit to GP
- Identify areas and spreading of good practice
- Connect with the carer and support them as required by the individual (not just passing information)

- NHS skills model could be embedded
- Employers need to make reasonable adjustment
- Carers support hub at scale not at individual practice level
- Good practice scale and pace

Table 8

- Healthcare training
- Assessments should be mandatory
- Need better and more truthful communications from professionals. E.g. How medications can affect people.
- Leaders need to influence what happens in their services and improve consistency across the patch.
- There are lots of third sector organisations that can help and health professionals need to know how and where to signpost people to.
- Professionals need to have the confidence at all levels to be able to signpost to people and not worry that they will be consequences if they signpost incorrectly.
- Need consistency throughout transition.
- There needs to be better/more communication to raise awareness of what services are out there.
- There can be a disconnect within organisation of what staff know.
- Need to check on discharge that carers are ok and can cope.
- There is too much expectation by professionals that carers know everything and where to go to get information etc.
- There needs to be better communication between agencies e.g. hospitals and GPs. They need to talk to each other and also communicate that to the carers.

Table 9

- Leaders need to be proactive in sharing good practice such as the Pudsey model.
- There needs to be awareness by NHSE of the danger of duplication in information gathered and the work done in identifying carers.
- Wider awareness and knowledge of the NHS website and the model that is being proposed – could there be agreement in the Health and Care Partnership to commit to testing the website/model in one locality in each of the six places, completing a thorough evaluation and peer review of the impact/benefits/issues etc. that the

localities have experienced.

- Promote the self-management agenda giving more control to people to manage their own needs with awareness that this may increase demand on services which are already thinly stretched.

Question 3

How do we know if this is working

Table 1

- Listen to see if carers think it's working.
- Use the NHS England markers
- Assessment, survey, audit, benchmark and then improve.
- One measure would be an increase in identification of carers.
- Another would be carers access to services improving.
- Consistency across WY & H – develop a survey, advertise and engage.
- Keep it fresh – don't wait 2 years to repeat and listen again.

Table 2

- Patient/carer surveys
- Conversations within the practice
- A choice of access options and other support is available; carers understand what is available and how to access them, at the point they need them (which can vary from person to person)
- Better use made of the facilities and resources that are already in place

Table 3

- Feedback is very important; the GP survey is a great way to monitor whether what we are doing is working.
- There is no need to reinvent the wheel we just need to utilise the tools we already have and get carers on the agenda of all the mechanisms.

- All too often carers are overlooked as people and are viewed just as carers, particularly as parent carers. We need to make sure carers are treated as people with care responsibilities.
- Communication is important and the type of communication needs to inform of the available services.

Table 4

- Carer's outcome tools – look at examples
- Measure what you can but accept that that some of the benefits are not measurable.
- See the development of a community services as evidence of success.
- Measure experience of patient's staff and carers.
- Look at how we release time for staff in practices to "care"
- Once the markers are used it will become clearer how to measure.

Table 5

- We need to identify risk in a constantly changing environment such as staff and funding etc.
- There is a need to realised we may work but require constant support
- Realise that this is a journey which will be working well at times and less so at others
- Sharing good practices and details of work GP's have done such as easy wins
- Repeat GP visit rates.

Table 6

- Look at the economic argument reduce the use of GP's and attendance to A&E
- Active recording of when people have been signposted - make greater use of this.
- Would carer's services know if things have improved?
- Do mystery shopping type checks with an understanding of carer's issues.
- Promote flu jabs for carers

Table 7

- We need to look at this from both a quantitative and qualitative point of view
- Look at outpatients, where evidence can be captured and identify carers are

receiving support.

- Culture framework and look at culture audits

- Healthy based team approaches

- Offer at local and WYH level

- Shared narrative

Table 8

- All agreed the quality markers are good work to do.

- More carers will be identified.

- For feedback possibly use an FFT style approach or tag something onto the existing FFT form.

- Better feedback will be received around access to services.

- Keep consistency by using the same measuring tools e.g. patient survey, which should demonstrate better feedback/results.

- Mandatory training for professionals. Could be by e-learning packages. After training not ask if this has been completed but also ask:
  - what will you now do differently as a result of this training?
  - How has this training helped you?

- Commissioners can evidence and build a business case.

- Should see an increase in the use of third sector organisations.

- Carers save the system money.

- Self-care and prevention is really important.

- Give carers a range of free services e.g. the flu jab – helps to keep carers well to allow them to keep caring.

- Is there a way to have some financial measurements? E.g. what would be the cost to the system if a carer becomes unwell and not able to keep up with their carer duties? What would be the cost to the system that carer is unwell and using services.

- "Need to keep the carer well"

Table 9

Difficult to measure as current methods of measurement are not reliable – Primary Care Survey, Adult Social Care Outcomes Framework Survey.

What may be an indication that changes are having an impact could be:

- Carers self-reported increase in confidence to manage their own needs as well as the needs of the cared for.
- Reduction in attendance at A&E, readmissions, falls, late diagnosis of health conditions
- Increase in carer health and wellbeing – self assessed
- Improved experience reported in on sites such as NHS Choices (current Primary Care Survey reports poor experience from a carer's perspective).

Appendix 7 – Event evaluation raw data

Presentation 1 – Welcome and Introductions	Presentation 2 – The purpose of the day - why should primary care support carers	Presentation 3 – NHS England's approach to supporting carers within primary and secondary care	Presentation 4 – The West Yorkshire and Harrogate Partnership Carers Programme	Presentation 5 – Our vision for carers in Primary Care	Presentation 6 – So what happens next	Is there anything else you would like to tell us?	Activity 1 - Table top discussion. Group work in themed discussions	Is there anything else you would like to tell us?	Registration	Welcome	Venue	Is there anything else you would like to tell us?	Any other general comments?
9	9	9	9	9	9		9		Very Good	Very Good	Very Good		Well organised event. Very informative information. I learnt about the primary care quality markers, annual healthcare checks for carers. Thank you

10	10	7	10	9	10	The NHS England quality measures for carers are tricky to understand - it was challenging to understand fully from the presentation. Prior to the session we were given lots of information as facilitators/scribes about quality markers being voluntary - to counter GP critique - but I don't think this was the message we really want to take away about this initiative - people should want to evidence how they help carers!	10		Very Good	Very Good	Very Good		Really well organised event with great pace and right balance. Well done to all involved :)
9	9	9	9	9	9		10		Very Good	Very Good	Very Good		
10	10	10	10	10	10		10		Very Good	Very Good	Very Good	Parent carers often caring for disabled children and elderly parents too. DOUBLE CARING RESPONSIBILITY	As a carer I would like to have seen the event being presented in partnership with carers. (Co-hosting, presenting etc)
10	10	10	10	10	10		10		Very Good	Very Good	Very Good		

9	8	6	9	8	8	Shame about technology issues	9		Very Good	Very Good	Very Good	Enjoyed the day. Looking forward to change	
8	8	8	8	7	8	Didn't feel rushed, but also felt moving towards discussion work after the break	9	Feedback went on too long - perhaps choose top thing to each question.	Good	Good	Very Good	Overall good event, well facilitated	Good to hear from carers as well as professionals
9	10	10	10	10	10	Fast			Very Good	Very Good	Very Good		Very good and informative
10	10	10	10	10	10	Excellent presentation. Very good variety of different professions.	10	N/A	Very Good	Very Good	Very Good		Excellent. Thank you
7	8	7	7	7	7	I feel we needed social care in the room	8		Good	Good	Good	Packs were very helpful	Feedback gets boring when people describe everything discussed - we could have had another 10 minutes valuable discussion
9	9	9	9	9	9		9		Very Good	Very Good	Very Good		
10	10	8	8	10	8	Interesting morning - very useful	10		Very Good	Very Good	Very Good		
10	10	10	10	10	10	Really interesting and useful event. Lots of different perspectives from different people but all with the same aim.	10	Great interaction by all and good facilitation	Very Good	Very Good	Very Good	Great event. Thank you for including us.	

7	8	7	7	8	8		8		Good	Good	Good	Several presentations would have benefited from venue / host preparation	Good event and networking on the topic Further detail on the offer from carer services and open conversation on where they need to improve would increase collaboration with primary care / PCH
8	8	8	8	8	8		8	Table talk was good	Good	Good	Very Good		
9	9	9	9	9		More awareness at local level about the carers programme	10		Very Good	Very Good	Very Good		
9	9	9	9	9	9		10						
9	9	9	9	9	9		8		Very Good	Very Good	Good		
8	9	6	8	8	8		9		Very Good	Very Good	Very Good		

Appendix 8 – Equality Monitoring Form

1. What is the first part of your postcode?

Example	HD6 / LS2
Yours	

☐ Prefer not to say

2. What sex are you?

☐ Male ☐ Female

☐ Prefer not to say

3. How old are you?

Example	42
Yours	

☐ Prefer not to say

4. Which country were you born in?

☐ Prefer not to say

5. Do you belong to any religion?

☐ Buddhism
☐ Christianity
☐ Hinduism
☐ Islam
☐ Judaism
☐ Sikhism
☐ No religion
☐ Other (Please specify in the box below)

☐ Prefer not to say

6. What is your ethnic group?

Asian or Asian British:

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Other Asian background (please specify)

Black or Black British:

☐ Caribbean
☐ African
☐ Other Black background (please specify)

Mixed or multiple ethnic groups:

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Other mixed background (please specify)

White:

☐ English/Welsh/Scottish/Northern Irish/British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Other White background (please specify)

Other ethnic groups:

☐ Arab
☐ Any other ethnic group (please specify)

	☐ Prefer not to say

7. Do you consider yourself to be disabled?

☐ Yes ☐ No

☐ Prefer not to say

Type of impairment:
Please tick all that apply

☐ **Physical or mobility impairment**
(such as using a wheelchair to get around and / or difficulty using their arms)

☐ **Sensory impairment**
(such as being blind / having a serious visual impairment or being deaf / having a serious hearing impairment)

☐ **Mental health condition**
(such as depression or schizophrenia)

☐ **Learning disability**
(such as Downs syndrome or dyslexia) or cognitive impairment (such as autism or head-injury)

☐ **Long term condition**
(such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)

☐ Prefer not to say

8. Are you a carer?

Do you look after, or give any help or support to a family member, friend or neighbour because of a long term physical disability, mental ill-health or problems related to age?

☐ Yes ☐ No

☐ Prefer not to say

9. Are you pregnant?

☐ Yes ☐ No

☐ Prefer not to say

10. Have you given birth in the last 6 months?

☐ Yes ☐ No

☐ Prefer not to say

11. What is your sexual orientation?

☐ Bisexual (both sexes)
☐ Gay (same sex)
☐ Heterosexual/straight (opposite sex)
☐ Lesbian (same sex)
☐ Other
☐ Prefer not to say

12. Are you transgender?

Is your gender identity different to the sex you were assumed at birth?

☐ Yes ☐ No

☐ Prefer not to say

Once completed please either leave on the table with your evaluation form or hand them both to a member of the team.

Thank you for taking the time to complete this form.

Appendix 9 – Equality monitoring raw data

What is the first part of your postcode?	What sex are you?	How old are you?	Which country were you born in?	Do you belong to any religion?	What is your ethnic group?	Do you consider yourself disabled?	Type of impairment	Are you a carer?	Are you pregnant?	Have you given birth in the last 6 months?	Sexual orientation?	Transgender?
LS17	F	36		Hinduism	Indian	N	N/A	Y	N	N	Heterosexual/ straight (opposite sex)	Y
BD10	F	48	England	No religion	White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	N	N	Heterosexual/ straight (opposite sex)	N
WF3	F	45	England	No religion	White English/Welsh/Sottish/Northern Irish/British	N	N/A	Y	N	N	Bisexual (both sexes)	N
BD1	F	43	UK	Christianity	White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	N	N	Heterosexual/ straight (opposite sex)	Y
WK8	F	56	England	Christianity	White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	N	N	Heterosexual/ straight (opposite sex)	N

BD2	F	55	England	Christianity	White English/Welsh/Sottish/Northern Irish/British	N	N/A	Y	N	N	Prefer not to say	Prefer not to say
HD4	F	26	UK		White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	Y	N	Heterosexual/ straight (opposite sex)	N
HD4	F	40	England	No religion	White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	N	N	Heterosexual/ straight (opposite sex)	N
BD6	M	56	England	Christianity	White English/Welsh/Sottish/Northern Irish/British	N	N/A	Y	N	N	Heterosexual/ straight (opposite sex)	N
BD2	F	38	England	Christianity	White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	N	N	Heterosexual/ straight (opposite sex)	N
WF7	F	43	England	Christianity	White English/Welsh/Sottish/Northern Irish/British	N	N/A	N	N	N	Heterosexual/ straight (opposite sex)	N
	F	56	UK	Christianity	White English/Welsh/Sottish/Northern Irish/British	Y	Sensory impairment	N	N	N	Heterosexual/ straight (opposite sex)	N

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