

# Dignity in Care

Experiences in Oxfordshire

Healthwatch Oxfordshire

November 2015

*“ I don’t want another report that sits on a shelf”*

*-Carer, focus group*

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# 1 Executive Summary

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Healthwatch Oxfordshire and Age UK Oxfordshire undertook a project from March 2015 to November 2015 to better understand dignity in health and social care across Oxfordshire.

Healthwatch led on a mixed qualitative and quantitative study, designed to find out if national dignity standards, or ‘Dignity Do’s’ were being met across Oxfordshire. The project included questionnaires for patients and staff which were made available online. Volunteers also completed questionnaires with patients in their health or care settings. A total of 161 patients and 57 staff responded. For the qualitative stage, six focus groups were conducted and 10 case studies of experiences were received to bring a depth of understanding to the project. Age UK led on promoting and developing the Dignity in Care Awards to highlight areas of good practice across the county. They sought nominations and assembled a panel of patients and lay people to make the awards (see Appendix 2).

The findings of the Healthwatch project were mixed. The majority of people in Oxfordshire who completed our survey reported that they have received services with dignity. However, the experiences reported by people who need communication assistance or have dementia, for example, were not always dignified, and in a small number of cases were shocking. The case studies and focus groups revealed details of how things can go wrong and tell powerful stories about the impact on individuals of receiving care that does not meet dignity standards. The staff survey findings show a workforce that believes strongly in the importance of delivering dignity, but which is feeling that workforce pressures are making it difficult to deliver.

Age UK received so many nominations of excellent examples of care, that we have increased the number of awards being made to celebrate when and where we get care right for local people in Oxfordshire. Full details of the Dignity in Care Awards being made as part of this project can be found in Appendix 2.

The main body of this report presents and analyses only the data gathered by Healthwatch Oxfordshire for this project. This analysis should be considered alongside the other data on dignity which commissioners and providers regularly collect. For example, each February Oxfordshire County Council takes part in a national survey of people who use adult social care. In 2015, 513 people responded to the survey in Oxfordshire and 90% said

they were satisfied with services with 5% expressing dissatisfaction and 5% expressing no view.

Oxford University Hospitals Foundation Trust takes part in the National Inpatient Survey. The 2014 survey had a response rate of 53% and 86% of respondents said they were always treated with dignity and respect, a further 12% said sometimes. 87% rated their care 7/10 or above.

Oxfordshire CCG uses extensive survey data, including the national patient survey programme and the friends and family test to assure themselves that the majority of patients in Oxfordshire have a very good experience of healthcare.

In addition to participating in national surveys, Oxford Health NHS Foundation Trust surveys the patients and service users of all its services at least once a year. Its internal surveys include four trust-wide questions which are then reported to the Trust Board. These are reported by Directorate with the Older People's Directorate being most positive with 85% of patients being involved as much as they would like in their care and having trust and confidence in their service or clinician. For the Adult Services Directorate, these figures vary more from month to month but in September were about 50%. In the Children and Young People's Directorate, about 50% were involved as much as they wished in their care and 80% had had trust and confidence in their service or clinician.

### **Key Findings and recommendations arising from the Healthwatch questionnaires<sup>1</sup>**

**There is much that is good about the way care is being delivered in Oxfordshire:**

- 93% (146) of patients responded they had been treated with dignity or respect 'some of the time', 'most of the time' or 'always'
- 58% (90) felt they had 'definitely' been listened to when planning health or care services
- 95% (147) of people had felt their right to privacy had been respected 'always', 'most of the time' or 'some of the time'.
- 88% (134) responded they had 'definitely' or 'to some extent' understood explanations of their care and treatment.

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<sup>1</sup> Responses to questions were not made compulsory. Some questions were routed meaning that the number of respondents to each question varies. The numbers in brackets after each percentage is the number of unique respondents that percentage represents.

- 95% (54) of staff strongly agreed or agreed they were satisfied with the quality of care in relation to dignity that they gave to patients
- 100% (56) of staff strongly agree or agree that patients were routinely treated with dignity and respect by staff in their organisation.

However, participants in all phases of this project identified significant areas for improvement. We had a breadth of responses to this project through all phases, in terms of the setting where people received care (hospital, care home, at home), but the numbers from each setting were small. Therefore our recommendations are made to all those delivering health or social care services in Oxfordshire and those commissioning the services, and are not specific to any one care setting. They are also made on the basis of the survey, focus group and case study findings. They fall broadly into two categories:

- **Improving communication**
- **Continuing to develop a workplace culture that supports Dignity in Care**

### **Improving Communication**

Some respondents to the study reported a feeling of being ‘done to’, suggesting that they are not actively involved in decisions about their care. We also heard about specific difficulties people had being heard because they couldn’t access advocates and interpreters, because their carers were not appropriately involved or because they didn’t understand what was being said to them:

- 77% (20) responded that they were ‘never’ provided with the communications assistance they required
- 31% (33) were ‘never’ or ‘occasionally’ informed of changes to their services, and when any new treatments would start
- 14% (14) reported that their care providers hadn’t appropriately involved people they had asked to be involved in their care
- 67% (24) who needed a formal advocate were not offered one
- 12% (20) felt their needs and wants were *not* taken into account by those providing services

### **Healthwatch Oxfordshire therefore recommends that:**

1. Communication be improved between staff and patients and their families, understanding that this communication must be two-way.
2. Access to support services which facilitate dignified care be more widely promoted and offered.
3. Discussions about maintaining dignity be included in staff training and induction, and that this training should include: dementia awareness, limiting jargon and using plain English, two-way communication and a broader understanding of dignity.

### **Continuing to develop a workplace culture that supports Dignity in Care**

During the course of the project we heard from a number of carers and some patients and service users that staff were not getting the balance between patient choice and dignity right. Examples of staff honouring the wishes of people with diminished capacity, where this choice may compromise dignity or healthy outcomes, suggested a discomfort amongst staff in negotiating difficult situations. Some respondents reported reactionary or defensive responses to initial concerns, and some said they had seen signs of staff being managed harshly - and this seems to have an impact on people's willingness and confidence to make complaints or raise concerns. Staff reported time constraints as a significant issue in their ability to provide consistently dignified care. Of the patients and service users who completed the questionnaire:

- 17% (26) didn't feel they had been helped to maintain a level of independence, choice and control that they were comfortable with
- 25% (39) had wanted to make a formal complaint about their care or treatment
- 44% (17) did not feel that they could complain without worrying about the consequences
- 11% (16) reported witnessing or experiencing abuse

### **Healthwatch Oxfordshire therefore recommends that:**

4. Providers and commissioners work to ensure staff have the time to care, by increasing the proportion of time they spend with patients. This could be done through continued work to improve



processes and paperwork, work to decrease staff sickness or through increasing allotted time for specific tasks.

5. Commissioners and providers in Oxfordshire broaden the discussion on dignity in work places, so that it encompasses all elements of dignified care (the Dignity Do's can provide a guide) and that this discussion inform training and the development of care models or pathways.
6. Staff be helped to focus on the balance between patient choice and dignity, particularly when patients have a diminished capacity to make choices.
7. Providers do further work to develop an open culture that learns from complaints and isn't defensive so that patients and carers feel able to make complaints/report abuse without fear of repercussions.

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## 2 Commitments to take action

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Oxfordshire County Council, Oxfordshire Clinical Commissioning Group, Oxfordshire University Hospitals Trust and Oxford Health Foundation Trust have all already committed to taking action in response to the recommendations made by Healthwatch Oxfordshire. Their responses are set out in full in Appendix 3 and have been summarised by Healthwatch below.<sup>2</sup>

### 2.1 Oxfordshire Clinical Commissioning Group

Oxfordshire Clinical Commissioning Group welcomes the recommendations made in the report. They monitor all providers to see that dignity in care standards are being upheld and seek to ensure through their contracts that patients with additional needs are appropriately supported by services making reasonable adjustments, and are provided with advocacy and interpreting services when needed.

### 2.2 Oxfordshire County Council

Oxfordshire County Council:

- Commission the Community Information Network which trains and supports volunteers to help people find out what is available in their own communities, making sure they have the opportunity to be active in their own wellbeing, independence and support when needed.
- Are working with other commissioners to develop a model of co-production that will see service users directly involved in the design and commissioning of future services.
- Are developing an e-marketplace that will offer individuals, carers and professionals the opportunity to choose and purchase good quality care and support services from providers specifically selected by the council.
- Runs campaigns that promote access to support services and equipment which facilitate dignity in care. For example, their current assistive technology campaign promotes the availability of devices that can be used in a person's home to improve their quality of life and that of their carer, and help them maintain independence.

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<sup>2</sup> Please note some respondents have given responses to recommendations made in an earlier draft which included just 6 recommendations.

- Commissioned a Community Information Network that operates across the county through information drop-ins, over the phone or visiting people at home, enabling individuals to access local support services, activities, financial advice and social care.
- Commissioned an expanded advocacy service in response to the requirements of the Care Act 2014.
- Have established a new contract for interpretation services as part of a consortium, led by the Oxfordshire Clinical Commissioning Group and including health providers. This will allow staff to access interpretation either face-to-face or over the telephone through a quick and easy online system.
- Has run workshops on addressing the initial problems raised by carers about the new self-assessment process, and is meeting carers about the self-assessment forms, to work with them to make further improvements.
- Hosts the Dignity and Dementia Champion Network, which examines the importance of dignity in the development of care models, and contributes to training.
- Remains committed to making sure that all visits for support at home are the right length for the person and provide the support they need, and in all cases are sufficient for care and support to be given with dignity and respect. All visits involving intimate personal care such as help with washing or using the toilet will be more than 15 minutes long.
- Supports providers to recruit people for their desire to work caring for others, and their commitment to values such as dignity and respect.
- Has developed Home Care Standards written jointly by people who receive care in their home and home care support agencies, and which require providers to meet dignity standards such as introducing themselves when they arrive and helping you at a pace that suits you.
- Ran a workshop for residential care home staff to explore the need to share learning from complaints, and views complaints as a positive tool to promote improvement in services.

## 2.3 Oxford University Hospitals NHS Foundation Trust Response

### OUHFT:

- Has co-produced a new Privacy and Dignity Policy with voluntary and partner organisations.
- Delivers a Trust wide weekly compassionate care training programme which is aimed at providing participants with an appreciation of the impact of behaviour and attitudes on the patient, and an understanding of effective communication styles with those who are vulnerable. A total of 322 employees have currently attended the training.
- Will review advocacy arrangements at the Trust with a view to ensuring

that access to advocates and other support is improved. For example, information will be put in patient packs to promote Oxfordshire Advocacy services more widely.

- Is undertaking a new piece of work with Independent Mental Capacity Advocates (IMCA) - to raise profile of IMCA services with consent to treatment and moving residents.
- Includes training on dignity and respect its Induction Day for all staff and will review this session and other training on dignity and respect.
- The Trust implements a 3 tier approach to delivering Dementia training to staff, ranging from simulation training using actors (Tier 2) for those staff working with patients with dementia every day, to awareness training at tier 1 for all staff in the Trust. There is eLearning to support all the face to face training. There is a cohort of Dementia Leaders (24) who were trained through a university short course so that they can in turn provide training to other staff in the Trust.
- The Trust is also in the process of implementing a means by which it can understand exactly how much 'direct' and 'indirect' time ( i.e. managing a complex discharge process ) Nurses and Nursing Assistants spend with patients.
- The Trust has recently implemented a new PALS escalation system for Inpatients in order to resolve issues speedily.
- The Trust is piloting and evaluating a regular Carers' Surgery, whereby Carers Oxfordshire are working in the JR for 21 hours a week on hospital wards offering support, advice and signposting for carers so that they can gain information and support.

## 2.4 Oxford Health Foundation Trust Response

OHFT:

- Will be consulting on a revised patient experience and involvement strategy from November 2015.
- Has introduced the use of the recovery star which supports the identification of joint goals and joint monitoring of progress across all community adult mental health teams, with training for all staff.
- Has developed a full programme of initiatives designed to embed personalised care and improve patient and carer involvement in planning their own care across all the Trust's services.
- Is working with Age UK to help older people to stay as independent as possible, to ensure they have the information they need and to introduce initiatives such as having volunteers working as care navigators at some of the community hospitals and dementia advisors working alongside staff in memory clinics.
- Has extensive relevant training programmes in place and will be making an additional recommendation to the next Learning and Advisory Group in December 2015 that the Dignity Do standards are taken into account when they design and review training courses going forward.

- Will review the current trust-wide core questions used across all patient surveys to include a specific question around dignity in care so that they can monitor and target improvements.
- Will continue the practice that all wards complete at least a 6-monthly review of the amount of direct care time spent with patients split by registered and unregistered staff, and will continue to present the results to the board of directors and to publish them, as well as asking each ward team to review the detail of their results to identify and make improvements.

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## 3 Background

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### 3.1 Background and introduction

Healthwatch Oxfordshire (HWO) and Age UK Oxfordshire initiated a project looking at how well national standards of dignity in care were being met locally, after hearing stories from service users<sup>3</sup> and patients who felt they had not been treated with dignity. Healthwatch Oxfordshire and Age UK Oxfordshire were keen for the voices of people who have experienced services and those who support them to be clearly heard, so that lessons can be learned from their experiences and changes implemented for improved services in Oxfordshire.

Dignity has been a longstanding priority and concern across the Age UK movement. For many years the charity has campaigned for greater attention to the problem of breaches of dignity and respect, in areas ranging from the basics of care such as toileting, eating and drinking and pain relief, to the fundamentals of treating recipients of care as human beings and ensuring good communication. Age UK Oxfordshire has campaigned passionately against poor practice, but it has also sought to celebrate and commend good practice through its ‘Dignity in Care’ awards.

Nationally, dignity in care has a high profile, which has been highlighted through a number of reports on failures in care, such as the Francis Report. In 2013 the National Dignity Council led numerous focus groups around the country to better understand what is meant by ‘dignity’ when it comes to health and social care. The 10 Dignity Do’s were developed out of this work. The Dignity Do’s act as standards by which one can assess the level of dignity in people’s care. They state that “high quality services that respect people’s dignity should:

1. Have a zero tolerance of all forms of abuse
2. Support people with the same respect you would want for yourself or a member of your family
3. Treat each person as an individual by offering a personalised service

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<sup>3</sup> ‘Service-users refer to people who access health or care services but who would not consider themselves ‘patients’ as they do not have an illness.

4. Enable people to maintain the maximum possible level of independence, choice and control
5. Listen and support people to express their needs and wants
6. Respect people's right to privacy
7. Ensure people feel able to complain without fear of retribution
8. Engage with family members and carers as care partners
9. Assist people to maintain confidence and positive self-esteem
10. Act to alleviate people's loneliness and isolation.” (Dignity in Care, 2015)

Although dignity can be understood and defined in many different ways, we have chosen to use the 10 Dignity Do's as a guiding definition of dignity for this project, due to the fact that they were co-designed with patients.

## 3.2 Methodology

The project was conducted in two phases and this report details the findings and makes recommendations for areas of improvement on the basis of the experiences shared with us. It has been reviewed for accuracy, before publication, by key stakeholders, including Oxfordshire Clinical Commissioning Group (OCCG), Oxford University Hospitals NHS Trust (OUHT), Oxford Health NHS Foundation Trust (OHFT) and Oxfordshire County Council (OCC).

In the first phase of this project, HWO commissioned a number of local voluntary sector organisations to undertake focus groups with their client or member populations. The local voluntary groups chosen were those who had raised a dignity related issue with us in the preceding year and included Guideposts Trust, The Asian Women's Group, 'My Life, My Choice' and Headway<sup>4</sup>. These organisations were also asked to solicit case studies of experiences related to dignity in care. Groups were facilitated using a discussion guide which can be found in Appendix 5. In total six groups were conducted and 10 case studies were undertaken. Some chose to do these in a written format, two produced video case studies. Case studies are available as Appendix 1.

The second phase of the project included questionnaires for patients and for health and care staff asking them to share their experiences of dignity.

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<sup>4</sup> Guideposts - [www.guideposttrust.org.uk](http://www.guideposttrust.org.uk), The Asian women's Group - [www.asianculturalcentre.org.uk](http://www.asianculturalcentre.org.uk), My Life, My Choice - [www.mylifemychoice.org.uk](http://www.mylifemychoice.org.uk), Headway - [www.headwayoxford.org.uk](http://www.headwayoxford.org.uk)

Questionnaires were made available online and shared through the media, the Healthwatch Oxfordshire and Age UK Oxfordshire websites, and through existing mailing lists. The patient questionnaire was also used as the basis of 95 interviews conducted across the county in Enter and View visits.

### 3.3.1 Enter and View

The Health and Social Care Act allows Healthwatch-authorized representatives to observe service delivery and talk to service users, their families and carers on premises such as hospitals, residential homes, GP practices, dental surgeries, optometrists and pharmacies. Local Healthwatch-authorized representatives carry out these visits to health and social care services to find out how they are being run and make recommendations where there are areas for improvement. Sites for Enter and View for this project included:

Date	Site
16 <sup>th</sup> June	Henry Cornish Centre - Chipping Norton Nursing home with an intermediate care area
22 <sup>nd</sup> June	Sandford Ward - Churchill Hospital Older people mental health ward (male)
23 <sup>rd</sup> June	Wintle Ward - Warneford Acute mental health ward (female)
24 <sup>th</sup> June	Citycom community hospital - Oxford
25 <sup>th</sup> June	Witney Community Hospital
30 <sup>th</sup> June	John Radcliffe Hospital Emergency department Maternity Outpatients (blue area)
1 <sup>st</sup> July	Horton Hospital Banbury Outpatients department Emergency department
2 <sup>nd</sup> July	Churchill Hospital Respiratory ward Dialysis ward
6 <sup>th</sup> July	Agnes Court - Banbury Care home
8 <sup>th</sup> July	Sue Ryder - Nettlebed Hospice



10th July	Brooklands (Banbury Heights Nursing home)
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### 3.3.2 Questionnaire Development

The patient questionnaire was designed by the project logistics group (a group made up of HWO staff, and representatives from each of OUHT, OHFT, the Orders of St. John Care Trust, and OCCG). It was designed to cover elements of the 10 dignity do's. The questionnaire was tested, first by HWO enter and view volunteers and then by adults attending the Banbury health and wellbeing day centre, revisions and alterations were made after each stage.

The staff survey was developed by Healthwatch Oxfordshire staff and reviewed by the project logistics group. As the logistics group was made up of health and care professionals from local commissioners and providers, further testing was not conducted.

### 3.3.3 Data Analysis

In order to ease access to the questionnaire, it was made available through a public link online. In order to ensure the data collected is as robust as possible, only one response was allowed from each IP address. Due to the public access to the questionnaires, up to a third of responses to each of the questionnaires were excluded. Criteria for exclusion included partial completions where there was too little data for analysis or where responses were clearly marked as 'test', for example. The data was also analysed to ensure that responses were genuine.

Some questions included a question logic. For example, only people who answered 'yes' to the questions 'did you want to make a formal complaint at any point in your treatment' were asked the follow up question 'if you wanted to make a complaint, were you able to do so without fear of retribution'. This was because it was felt that those who had received poor care, and who had wanted to complain, may feel differently than those who had a positive care experience. Some questions which were not routed included a 'not applicable' or similar response option, and these responses have been removed from the analysis, as they provide little information but skew the statistics. The numbers for those responses are included in the data tables, appendix 4.

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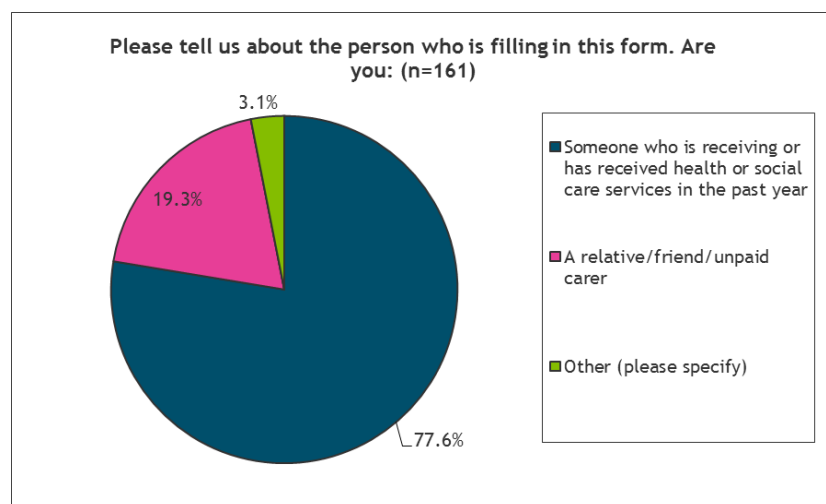
## 4 Views from patients and service users

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This section details the views of patients and service users on dignity in care. It outlines the results of the questionnaire, to which 161 people responded. These are presented in themes as many questions related to each theme or aspect of dignity.

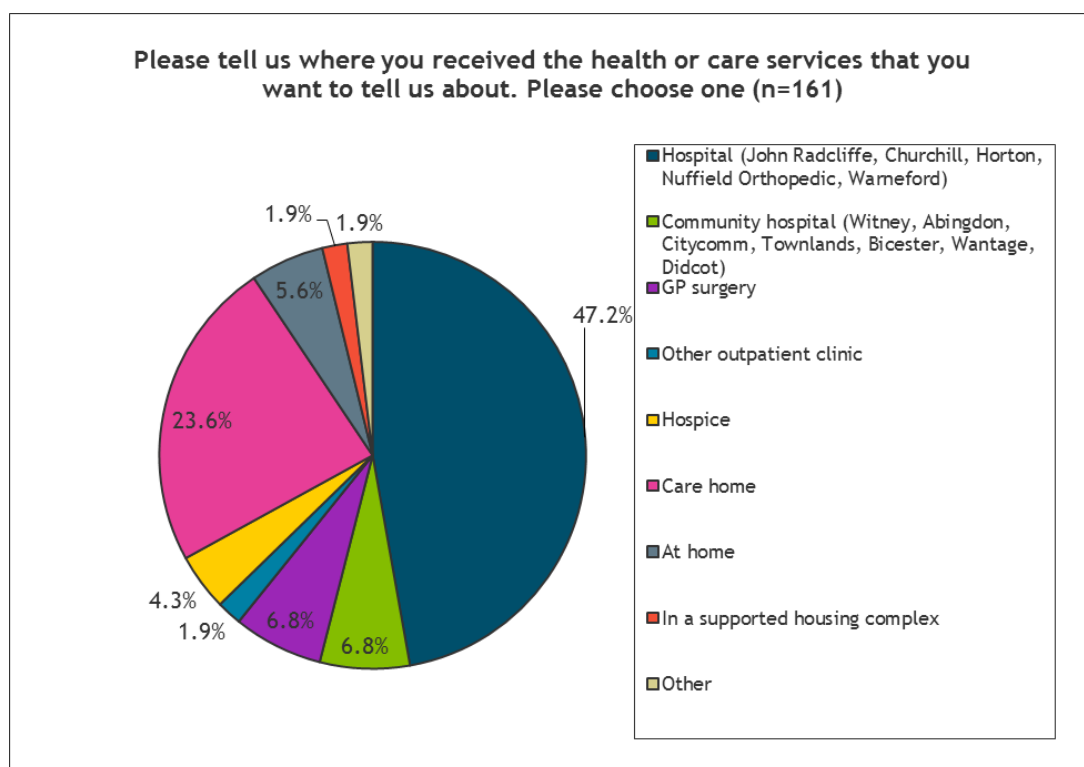
### 4.1 Respondent profile

Views from patients and service users were invited through an online questionnaire and through enter and view visits. A total of 161 people responded to the questionnaire 59% (95) of which were through enter and view visits. As these visits were conducted within the setting in which they were receiving care, we can expect a slight positive bias to the responses. 47% (76) respondents reported their experiences from acute hospital, 24% (38) from care homes and 7% (11) from each community hospitals and GP surgeries.



59% of respondents identified as female, and 41% as male. 79% of respondents were over the age of 50, the largest group of which were ages 61-70 at 27% (41). 54% (82) of respondents said they had a disability, though for some at interview, this was described as temporary - relating to their current episode of care. The respondents were primarily white, British, with 93% (141) identifying themselves that way.

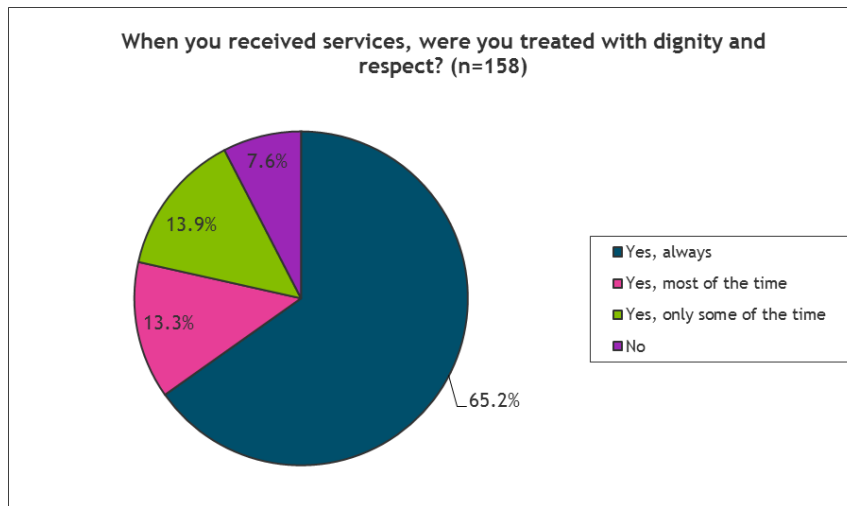
Owing to the profile of respondents, particularly that they are predominantly white, British and older, we would expect to see a slight positive bias to these results, as has been seen in patient experience studies such as the national patient survey programme and the Friends and Family Test (Sizmur S K. K., 2013) (Sizmur S G. C., 2015).



Around half of the responses came through the online link, many of which were received soon after the media coverage of the project. As with all forms of feedback, it is possible that those interested in complaining might be more likely to have filled out the questionnaire. Therefore, we expect that the positive bias expected from the Enter and View sample and demographics, may have been balanced in this way. It is important that this report be interpreted with these elements in mind.

## 4.2 Views on dignity and treatment

On the whole, respondents to the survey felt they had been treated with dignity and respect, with 65% (103) saying they were ‘always’ treated with dignity and respect. Only 8% (12) said they weren’t treated with dignity and respect and 14% (22) said they were treated with dignity and respect ‘some of the time’.



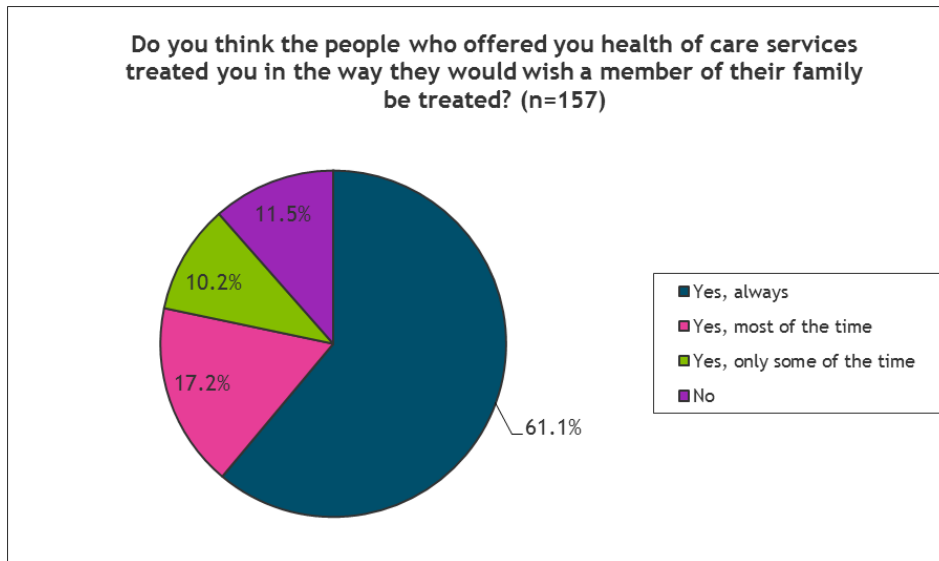
Comments relating to dignity and respect ranged from positive testimonials to dedicated and caring staff to instances of poor care. Where people felt they weren't treated with dignity, a number of comments dealt with elements of basic personal care such as washing or toileting, staff without appropriate training or brusque staff attitudes.

*When I first came here I wasn't feeling very good but I have always been treated with dignity. They have always been courteous to me and allowed me to ask questions.*

*Some carers are unaware that certain forms of dementia can lead to disinhibited behaviour (ie verbal or physical abuse). They were upset when the resident displayed this type of behaviour, taking the insults personally. This affected their ability to treat the resident with respect and dignity.*

*Live in carers were provided by [team] to my terminally ill mother in law. She needed help getting to the toilet at night but live in carers are not meant to be disturbed during the night which meant she would have to try and hold on. Problem got worse when she needed two carers to help her sit on commode. [They] wanted her to wear continence pads to get round problem but she felt this extremely undignified. She also had sores on her bottom so this was also not clinically appropriate. [They] refused to accept opinion of [other professional] on this and tried to come and examine her bottom for themselves when she was very close to death and any examination extremely painful. This was totally inappropriate.*

61% (96) of respondents felt that the people offering health and care services had 'always' treated them in a way they would want a member of their family to be treated. However 12% (18) did not feel they had been treated in this way, with a further 10% (16) feeling they were treated this way 'only some of the time'.



In some care settings patients discussed ‘feeling like one of the family’, this was particularly the case where people were there long-term, or were there repeatedly over time. Again, the kindness of staff was mentioned several times, however, patients had noticed that staff seemed short on time.

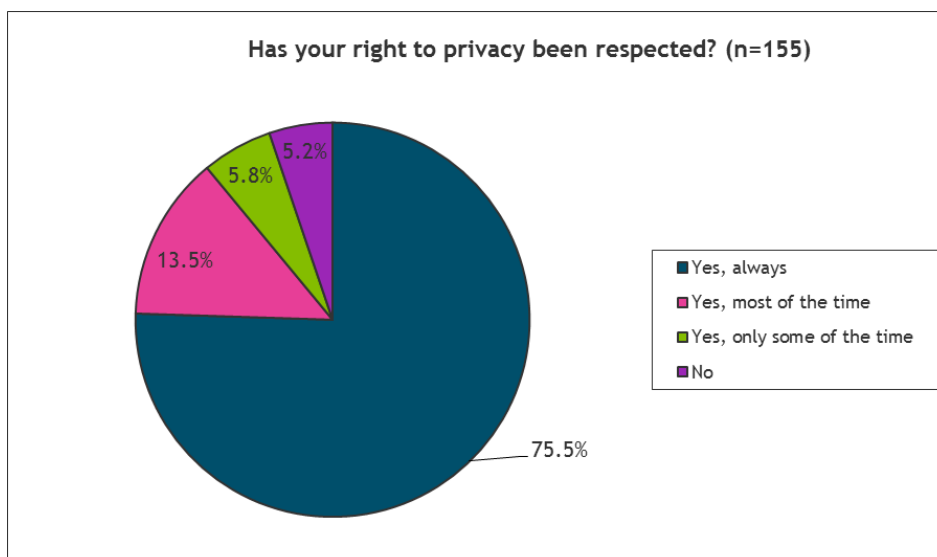
*I know all the sisters and staff. I feel like one of the family. They are lovely and really look after me.*

*Never seen any unkindness people in here with dementia very awkward am amazed at their patience. So quiet sweet and nice and kind.*

*Varied depending on who the staff team were*

*This is hard to answer because they are very short staffed and it shows. I have been kept waiting just to go to the loo, have a wash or a drink. It is not the staff's fault. They do their best.*

When asked about privacy, 76% (117) of patients reported this as ‘always’ being respected, and 14% (21) as ‘most of the time’. 6% (9) said this was respected ‘only some of the time’ and 5% (8) said their right to privacy was not respected. Patients reported that some of the time, due to their condition, their treatment was not possible with full privacy, due to mobility or other reasons, and this seemed a compromise that they were willing to accept. However, some people reported instances where attempts to facilitate one’s right to privacy weren’t attempted.



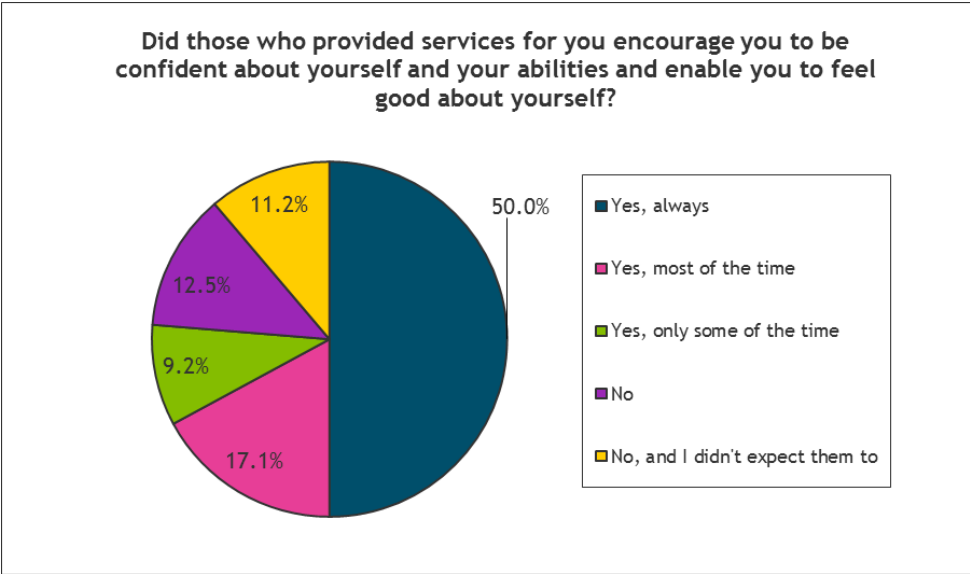
*Treatment Outstanding. Doors closed, ask if they can help. Wishes respected.*

*Staff always knock and wait for an answer before they enter my bedroom, they know what time I like to be woken up and what time I like to go to bed*

*My husband's wasn't at [care location] if you mean sitting in a public corridor for nearly two hours in a skimpy dressing gown*

When asking about the last two statements of the 'dignity do's', (Assist people to maintain confidence and positive self-esteem; Act to alleviate people's loneliness and isolation) there were differing reactions. For people who were in residential or in receipt of long term care, they seemed particularly relevant and important, whereas patients within Outpatients, for example, were confused to be asked about loneliness or their feelings of self-worth. Several patients mentioned, 'not being a lonely sort of person' or 'being used to living alone' when asked about that question.

Half (76) of respondents reported 'always' being encouraged to be confident about themselves and their abilities; 13% (19) feeling they had not been. A further 11% (17) had not expected the people providing their services to do this.

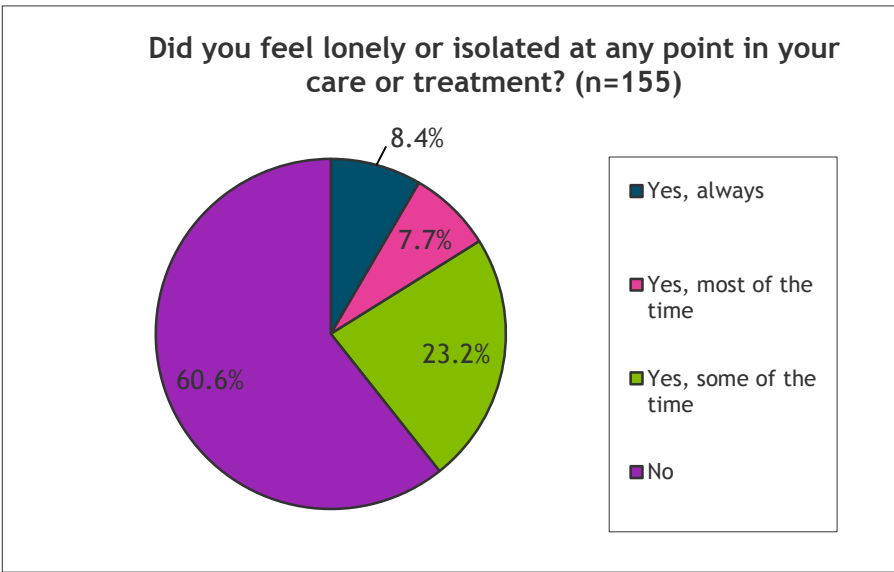


*They worked with people. Always calm, respectful and loving without being oppressive.*

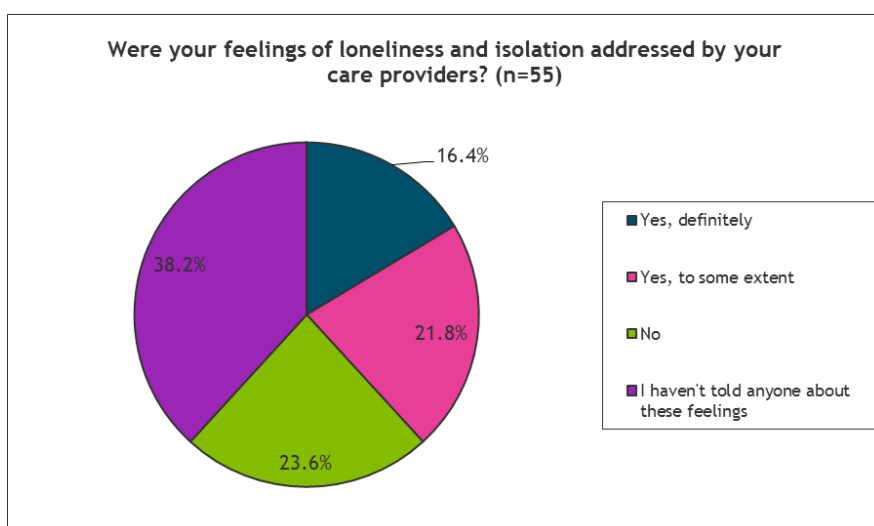
*With my depression, have some bad days and staff talk to me and show kindness.*

*Well I have lost a leg, going to make life difficult. Working like they are going to get me home for which I am grateful. Doing their utmost to make sure i can live at home independently. I am what you call a self-funder.*

The majority of respondents 61% (94) had not felt lonely or isolated at any point in their care or treatment, with a further 23% (36) having ‘some of the time’ felt that way. 16% (25) had always or ‘most of the time’ felt lonely or isolated.



When asked whether care providers have addressed the issue of loneliness and isolation, the largest number of respondents, 38% (21) said they hadn't told anyone about their feelings. When describing why this might be, many people mentioned, not wanting to 'bother' them with such things. 23% (13) of respondents reported that their feelings of loneliness and isolation had been addressed and a total of 38% (21) said their feelings 'definitely' or 'to some extent' been addressed by their care providers.



*They have tried to make me feel good.*

*Carers were advised to spend 10-15 minutes each day chatting to my mother. They have done this and she has become more reassured and contented. It has also helped the carers to understand her better, as they need to learn by observation as her dementia prevents her from explaining her behaviour, needs and concerns.*

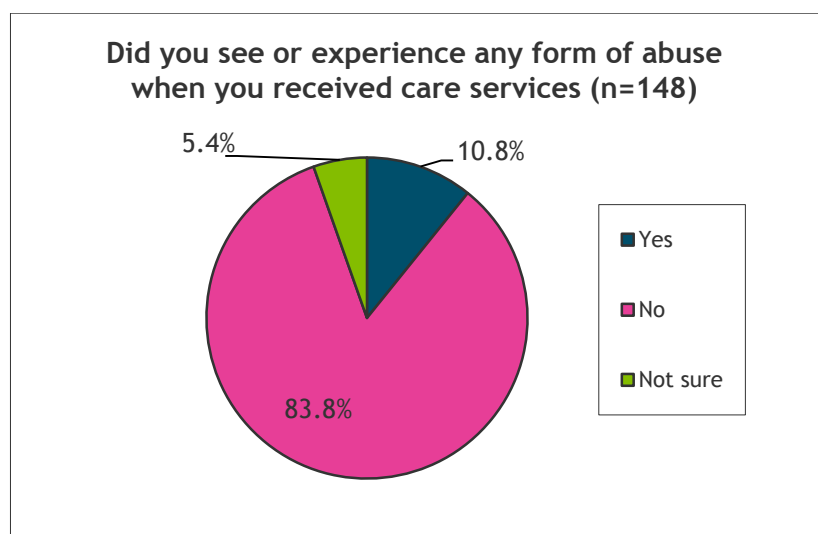
*I had to beg to be taken from my room to have some fresh air as the weather was very good. This only happened twice for about 10 minutes as the carers did not have time.*

Two questions were asked on the subject of abuse. The first question included a preamble on the definition of abuse, and made people aware of HWO's safeguarding policy.

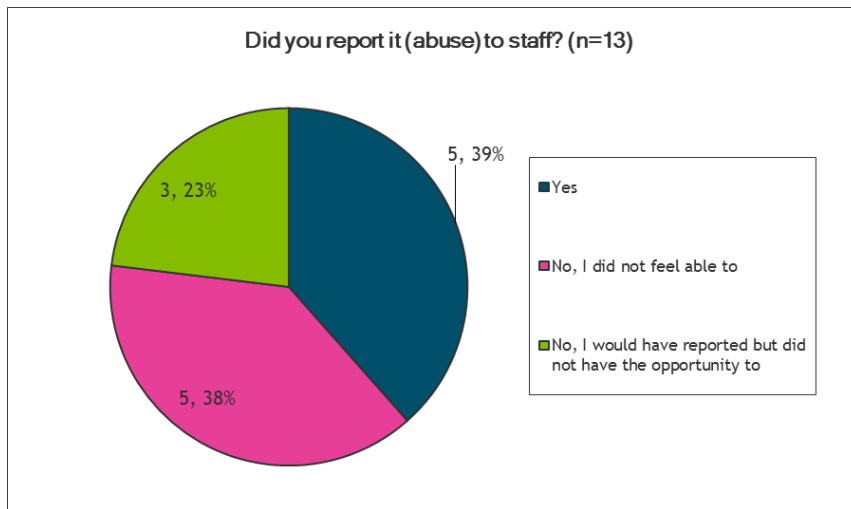
11% (16) of respondents said they had witnessed abuse or had been abused with a further 5% (8) who were 'not sure' if they had witnessed or been abused. The vast majority of respondents 84% (124) did not witness or experience abuse while receiving care.



Of the 24 people who had witnessed or experienced abuse or were unsure if they had, 3 had their cases referred to the OCC adult safeguarding team. Three respondents were not able to or unwilling to disclose the details of the abuse they were reporting. One respondent had previously referred the incident to the safeguarding team, two were reporting abuse of staff from patients. The remaining concerns highlighted incidences of very poor care, but we wouldn't consider them to be abuse within the context of our safeguarding policy. We have not included free text comments in this analysis as the details made them too identifiable.



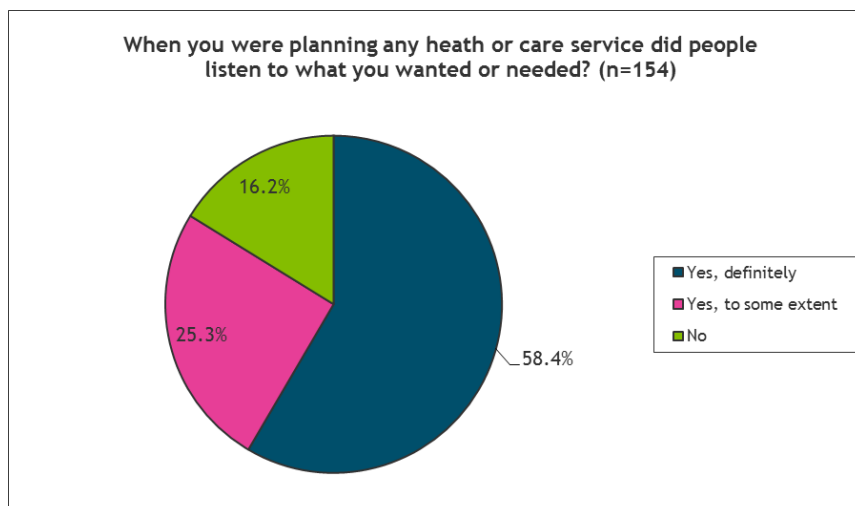
13 people answered a follow-up question about reporting instances of abuse. 5 had reported the abuse to staff, 5 had felt unable to and 3 did not have the opportunity to report abuse. This highlights that there may be a number of people who either don't feel confident in the system for reporting abuse, or were unsure to whom they should report the abuse.



### 4.3 Views on communication

Patients were asked several questions about communication. Responses to these questions uncovered some significant problems with how health and care services are communicating with people in their care. Patients mentioned ‘jargon’ or ‘speaking a different language’ (referring to medical terminology) to the medics and nurses caring for them. Additionally, patients highlighted the gap between staff listening, and understanding and acting on what patients had communicated. Patients and service users who required assistance with communication reported having particular difficulties in accessing the support they needed.

Over 1 in 7 people, 16% (25), reported that that when planning any health or care service, people did not listen to what they wanted or needed, however a slight majority 58% (90) felt they ‘definitely’ had been listened to.



A few patients mentioned feeling an expectation, from health professionals, that they should ‘passively’ accept whatever treatment was recommended. Those in residential homes, or receiving long term care were more likely to report having had discussions about their needs and wants, but these weren’t always updated as their care needs progressed.

*When I was admitted I was very ill and not able to communicate what I wanted. But now I can ask and I have no problems saying what I need and want*

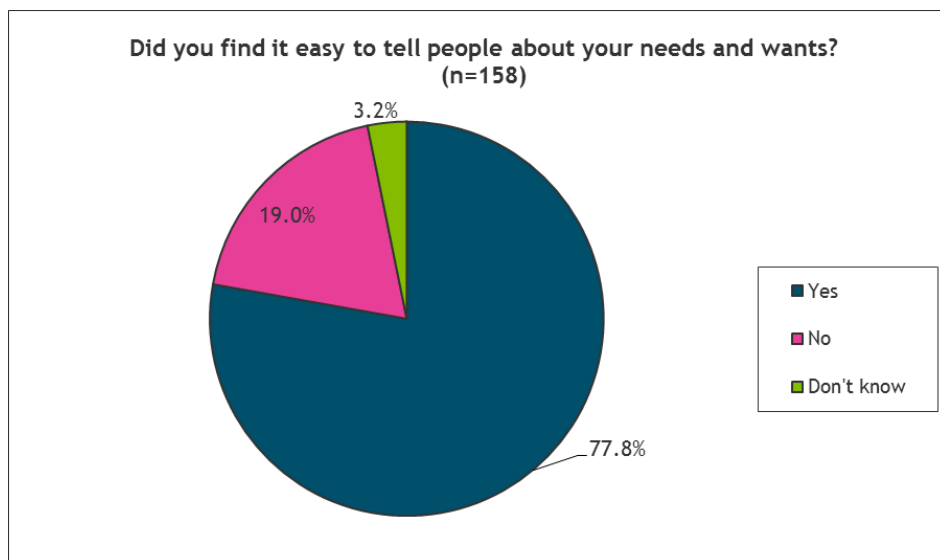
*I was supposed to be a passive package accepting that others knew best.*

*It didn't really apply as I was in an acute ward. My job was to be passive!*

*When he went into respite in the second home, they wanted to know his background, likes and dislikes and wanted to make their service individualised. They asked us to bring in a box of photographs - and a few little things about his life.*

*The care plan was made when she first went home but not reviewed as her condition deteriorated*

When asked whether they found explaining their needs and wants to be easy, nearly 1 in 5 patients responded it wasn’t easy 19% (30). 78% (123) did find that it was easy to tell people. The reasons for this variation were outlined by patients, from the nature of their needs and wants being a difficult thing to discuss with someone they do not know well, to relative levels of assertiveness (or passiveness) amongst patients.



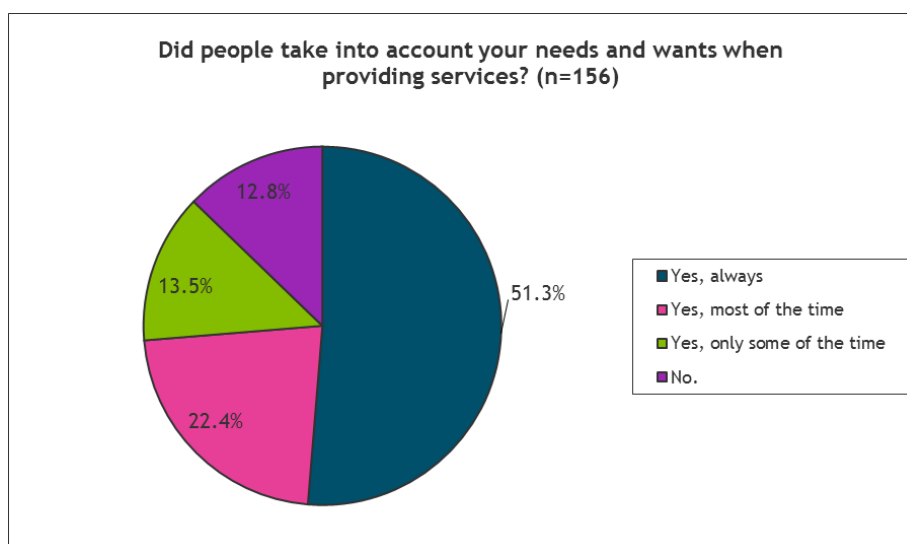
*I can ask for anything. If I see something wrong I tell them and they act on it.*

*Embarrassing as 26 year old doctor and nature of the problem.*

*I feel that I can articulate my needs quite clearly and assertively. I do not have a problem about speaking about my needs and what needs to be done for me. I often find care agency sends me that new and inexperienced carers because I end up training them!*

*Yes, but there is a difference between telling people and them listening and or understanding*

Only a slight majority 51% (80) reported the experience of ‘always’ having their needs and wants taken into account. 13% (20) reported that people had not taken them into account and a further 14% (21) as only some of the time.



When asked about taking into account needs and wants, a dichotomy emerged between wants and needs. This was particularly strong for patients with dementia. Several family members and carers spoke about the line between the importance of choice and the appropriateness of offering choice.

Where a patient didn't have capacity to make choices about their care, staff too frequently decided to follow the patient's choice, rather than meet their (sometimes clinical) needs. Examples included patients who were not changed and cleaned after soiling or wetting themselves, because patients had 'chosen' not to or where patients were still in bed late into the afternoon because they had 'chosen' to stay in bed. Challenging behaviours associated with dementia were thought to be one cause, but this ruling of

choice above all else significantly impacted on dignity and was difficult for relatives to witness, and in some cases make it difficult for them to advocate for change with their care providers.

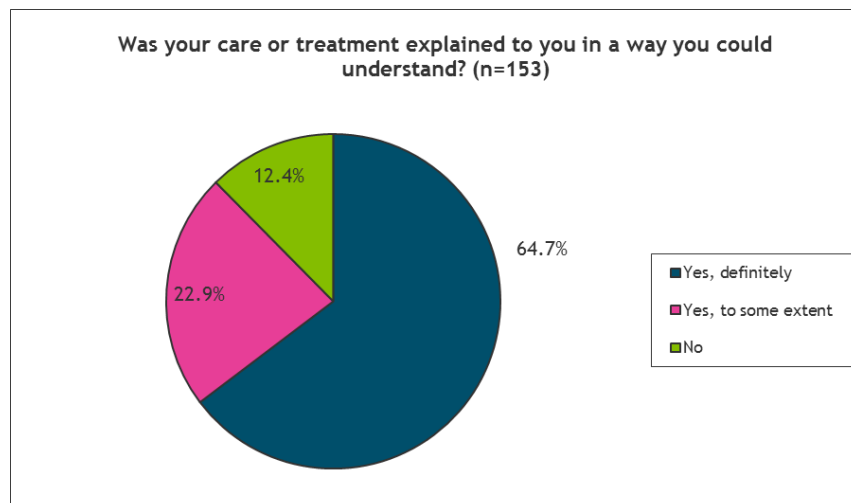
Some patients had a positive view, and had witnessed improvements over the years in how they were involved in their care, but felt there remained some room for improvement.

*Things have changed massively over the years. Take into account of disability, don't push you out.*

*They did around some things - like supporting my mother in law to be as independent as possible when she was still able. However the big issues was food - and toileting. It would have been nice for my mother in law to have had decent food in the last three months of her life - not just reheated microwave meals.*

*But it was their version of my needs.*

Over one third of respondents 35% (54), either did not understand explanations of their care or treatment or only understood 'to some extent'; 65% (99) had 'definitely' understood. Patients again referenced 'words that were hard to understand', 'poor English' and 'strong accents' as reasons for why people could not understand their care and treatment.



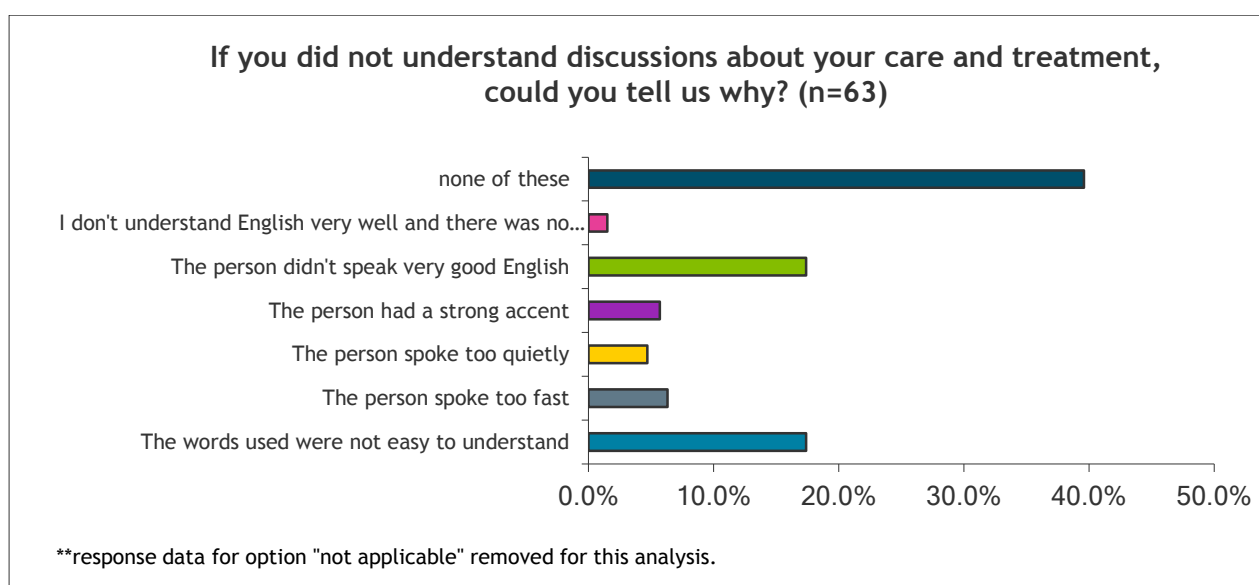
*Found some parts of the treatment confusing*

*Talking in medical language. Did apologise and explained in layman's terms. they were using jargon.*

*Most of the time, I think I've taken it all in but later I'm not so sure. Doctors they reel it off because they do it all the time. Perhaps they could take more time to explain but they haven't got the time.*

*Didn't really understand what they were saying some of the time. I didn't speak the same language as them.*

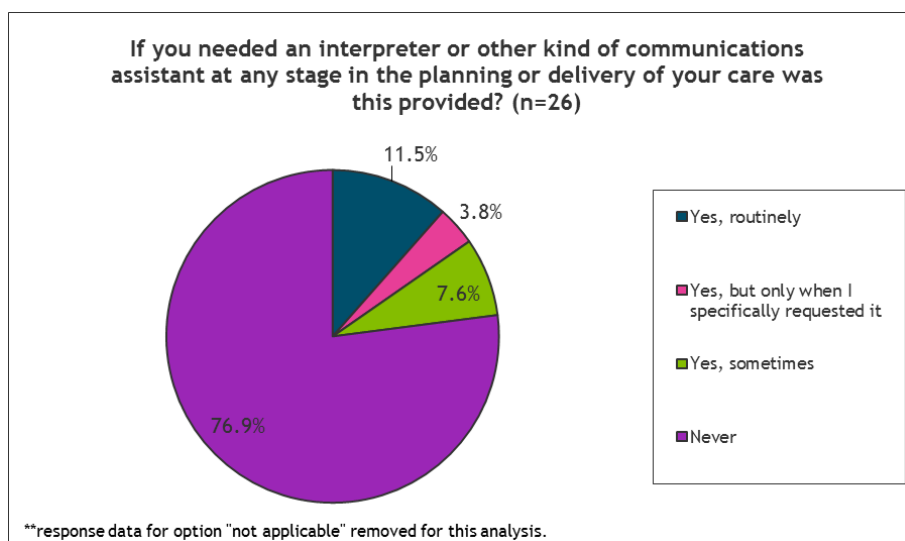
*Very detailed and complex care plans that were difficult to work your way round at times. It was also quite obvious that the Care staff would never read them as there would never be any time to do so. Any information was given at handover time and this was really poor*



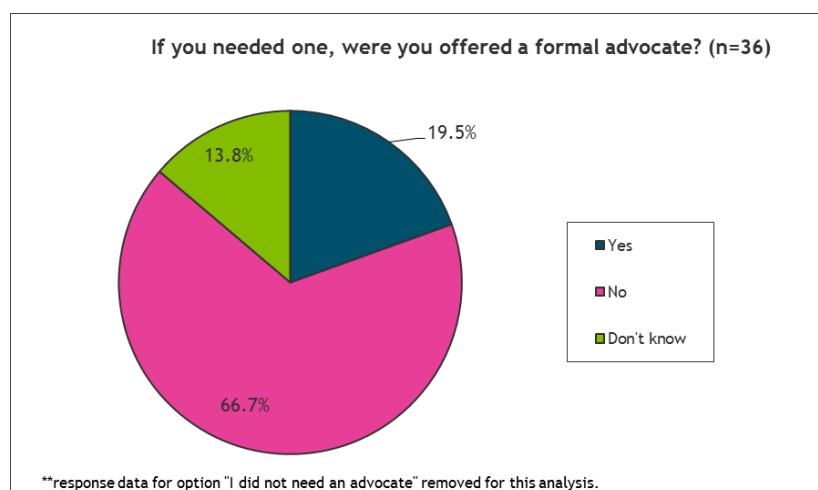
Of people who required communication assistance or interpretation, 77% (20) reported never having assistance provided at any stage in the planning or delivery of their care. 2% (3) had this routinely provided, 1 respondent received this when they specifically requested it and 1% (2) sometimes had assistance provided. It is a fair assumption that not being able to communicate with someone places a significant barrier to being able to deliver care that is dignified as that person is unlikely to understand their treatment, who is treating them or indeed give consent to be treated without being able to communicate easily. One patient described the positive experience of being assisted to communicate:

*I am able to speak and explain my needs. However I needed to get voice-activated software so I could use my computer. My daughter assisted me with this, but she does not live with me. The specialist occupational therapist assisted me in using this software which has made a tremendous*

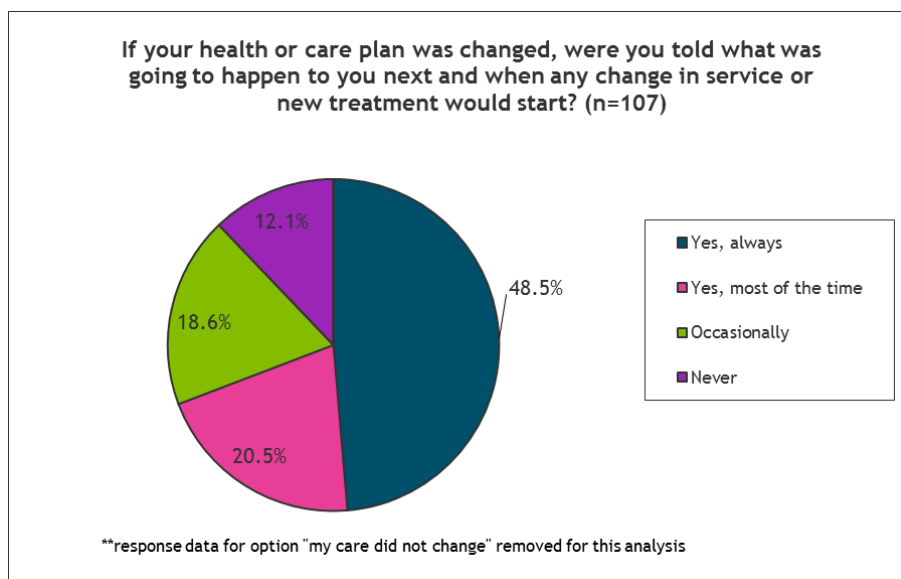
positive impact. I am very grateful for this support. I cannot praise them highly enough.



Similarly, of the 36 people who needed a formal advocate, 67% (24) of them weren't offered one adding to communication difficulties. Only 1 in 5, 20% (7) were offered an advocate. Of the 12 people who said they had an advocate, half of them couldn't comment on whether people providing their care cooperated with the advocate, with 5 agreeing they had cooperated and 1 saying they didn't cooperate with them.



Changes to care plans were another area where difficulties in communication arose. Just under half 49% (52) said they were told what was going to happen next and when any change or new treatment would start and 20% (22) were told most of the time. 12% (13) said they were never told of any changes, 19% (20) were only occasionally told of changes...



*I'm always well informed.*

*I called on several occasions to find out if there had been any updates/recommendations and was told this first had to go through senior management and I very rarely was updated on what was discussed and any outcomes.*

*My health care plan took quite a while to prepare. There were various people involved with this and the people kept changing so I was never sure who to contact... People change jobs or went on sick leave so when I telephoned I never knew who to speak to. Often my health needs changed but there was no one to change my care plan to keep it up to date. The care agency was working with an out of date care plan hence my caregivers were not trained to cope with my various needs....*

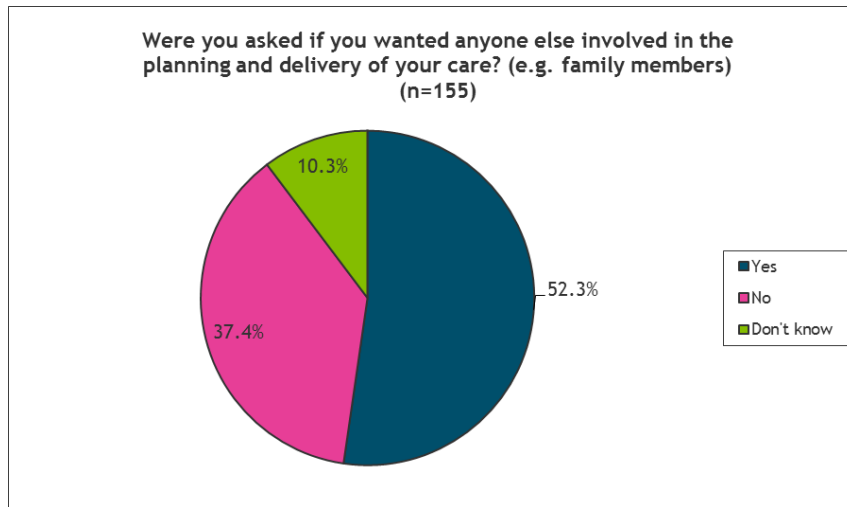
## 4.4 Views on involvement

52% (81) responded that they had been asked if they wanted anyone else involved in their care with 37% (58) saying they weren't asked. However, many participants, when asked this question said the involvement of their family members was implicit due to the fact that they attended or made appointments for them in their capacity as carer.

This is reflected in the follow up question on whether family members were involved appropriately in care; which can often be a difficult line to navigate for staff. 58% (57) people said their family was involved appropriately and a further 24% (24) 'to some extent'. 14% (14) respondents believed their family hadn't been appropriately involved. For those who felt their family hadn't been involved, it was usually due to the amount of

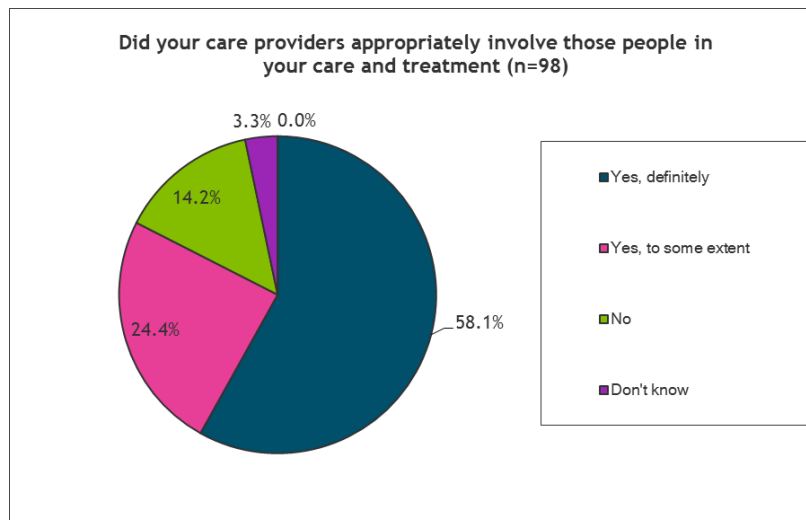


information delivered and the timing of that involvement. Carers responding, mentioned their 'expertise' of their relative's needs being undervalued by some professionals.



*My family keep in touch with staff via e-mail and they all update me so I feel connected.*

*But little information given and daughter [professional] was needed to give injections but with no guidance.*

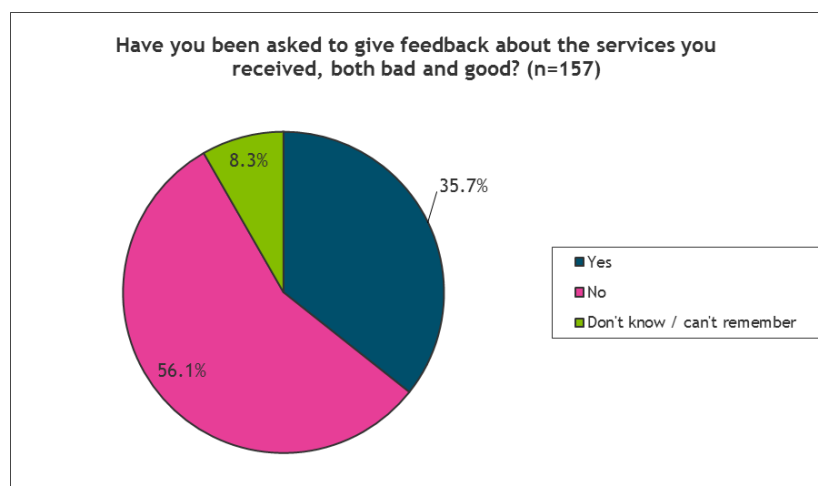


## 4.5 Views on feedback and complaints

Two questions were asked about feedback and complaints. The first asked whether patients and service users had been asked to give feedback about their care. Considering that nearly half of the respondents were still within

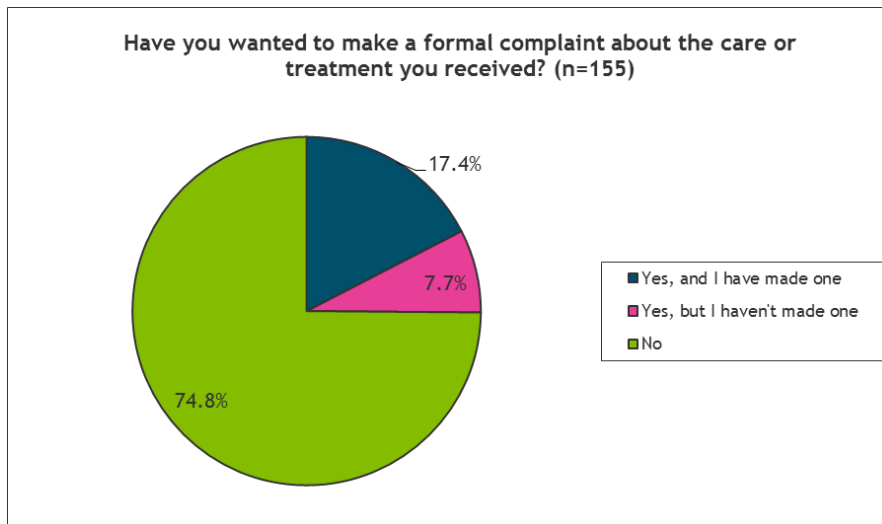
the health or care setting where they were receiving care, and that the Friends and Family Test, and other routine feedback mechanisms are delivered on discharge, the responses are not surprising.

56% (88) of respondents had not been asked to give feedback about their experience, and 36% (56) had been asked. 8% (13) could not remember.



A quarter of respondents (39) had either made a formal complaint or had wanted to make a complaint but did not make one.

This number seems to be much higher than we would expect given the number of complaints received by local trusts in comparison to their overall throughput. This could be because patients describe a complaint as ‘formal’ when they register it with a member of staff such as the ward sister, or contact PALS, or make it in writing, but Trusts only count complaints made through the formal complaints process. Or it could be down to services users being more confident talking about complaints to an independent organisation like Healthwatch.



*Raised an informal concern with the manager, worried about getting into trouble if I complain but the manager reassures me that I won't get into trouble.*

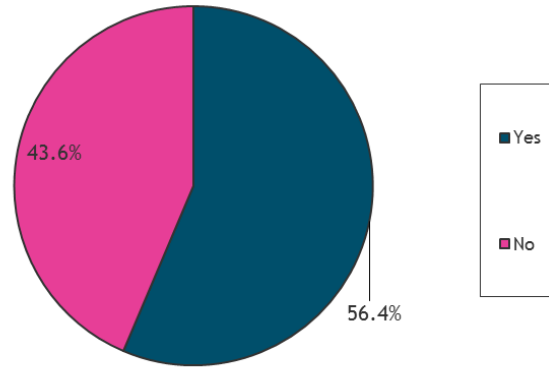
*WE felt we could not complain when she was alive as they might withdraw her care. After she died it took some months for me to be able to coherently write about most (not all) of the awful things that happened in that time. I sent letter wanting them to learn from our experience so it would not be repeated for others. They responded to say they are treating it as a formal complaint, that someone would be in touch shortly and they would complete the process by [date]. I have heard nothing since- and it is the [date]. Not feeling very confident in this process but about to fire off another email.*

*I haven't made a complaint because I feel that it wouldn't make a difference.*

*Had a thank you from Chief Exec office*

A follow up question was asked only to those who had wanted to complain. The rationale behind routing the questions in this way was that people who had received poor care, were likely to feel differently about complaining than those who had received good care. This might play out in two ways. The experience of poor care leading to making a complaint may undermine one's confidence in the system overall, but it may also change feelings of empowerment if one received poor care. 56% (22) felt they could make a complaint without worrying about the consequences, and 44% (17) did not.

If you wanted to make a formal complaint did you feel able to do so without worrying about the consequences? (n=39)



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## 5 Views from patient focus groups and case studies

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HWO commissioned local voluntary sector organisations to undertake focus groups with their client or member populations. The groups chosen were those who had raised a dignity related issue with us in the preceding year and included: Guideposts Trust, The Asian Women's Group, My Life, My Choice and Headway. A total of 6 focus groups were held in March-April 2015. Full transcripts of each Patient Story and the reports from each focus group are included at Appendix 1.

An HWO associate attended all of the groups, but the groups were facilitated by the organisations commissioned to conduct them. Organisations were asked to follow a semi-structured topic guide to facilitate the groups. The guide is included in the report as Appendix 5.

Local organisations were also asked to provide some case studies. As personal stories of care can provide a powerful understanding of what dignity means, what elements of care people are important for people, and what the impact is when things go wrong.

The groups were invited to participate in order to understand the experiences of those who had suggested previously that their dignity needs had not been met, this section should not be seen as representative of all experiences in Oxfordshire. Rather, as with the approach to learning from complaints, often particular lessons can be learned from those who have the most negative experiences of care.

We have tried to report the findings from this stage of the report in the participants' own words, and only organising the verbatim quotes into highlights, low points and the major themes which emerged: cultural sensitivities; staffing capacity and funding issues; communication; privacy; dignity and choice; advocacy; and appointment waiting times.

### The highlights

*Day centre staff take me to the activities I enjoy - swimming horse riding, outings. Day centre care is really good at [location]. Everyone is so*

*friendly and I enjoy the activities. The respite staff are so welcoming and friendly and I really enjoy going there.*

*They notice when my husband is out of sorts. They care about him as well as for him. They treat everyone as individuals.*

*S said that [voluntary sector org] has always supported her with dignity and respect. When she was at her lowest point and everything seemed like an uphill battle they helped by setting small goals and making sure she had lots of 'little breakthroughs'. They helped her to get organised in her paperwork and to get her finances sorted.*

*... lack of space meant that my father in law was living in the living room. The carers came in twice a day to cleanse, change and help bath my father in law and were very respectful of his condition and the family situation. They would smile and talk to him as if he understood and share a joke with him, he would respond with a smile and felt comfortable with female carers. They respected his wishes when he refused to have a bath and listen to his and the families concerns.*

*They would ask when it was convenient and if there is anything that they needed to be aware off on a daily basis. They became a part of our family.*

*The care here is good, and that extends to us as carers too.*

*Mum is respected and given choices here.*

## **The low points**

*I felt at times my aunt is neglected at the care home she is in. For example, her drink would be propped up on her blanket, with a biscuit on her shoulder. She can only use one finger and thumb on left hand. She needs feeding and is frail now. She is fed yogurt although I have told them she hates it.*

*Have had a series of operations due to stroke. I reacted badly to anaesthetic and so I was completely loopy for 3 months whilst on a ward. I was left for hours in my piss and shit, I was sedated and my health needs were neglected. None of the '10 Do's' were there. It is a completely aspirational list. I have seen no attempts to put it into practice - only lip service.*

## Cultural sensitivities

*I think the most important thing is respecting the person for who they are. Respecting their culture, respecting their religious needs respecting their family needs. I know that they can't meet everyone's needs but at least understanding that this is their needs...*

*I am a [older, nationality] woman and cannot speak, read or write English I can only speak my [language]. I have three children who care for me at home because I have [conditions] that affects my mobility. I was admitted in to hospital for a knee replacement. My son was with me before I went in to the operating theatre so I felt safe. My son had expressed for a woman nurse to look after me but from time to time a man would come and check me. In the evening a male nurse came to change my bed I refused and said no but still he helped me out on to the sofa and fixed my bed. I was so embarrassed and upset felt so alone and helpless because I was not listen to and I was not respected.*

## Staffing, capacity or funding issues

*I think the care package from the adult mental health team is insufficient.*

*It's impossible for Carers doing 20 minute home visits to shower someone, dress them, give them their breakfast and their medication. I can't even do that for myself.*

*There are not enough activities at [location] or enough care staff, which of course affects how people feel about themselves. This is driven by [commissioner] capping the fees at an unsustainable level. The motivation of the staff and management are excellent but their budget is insufficient*

*Overall the care is very good here, but these people are very busy....he loves a game of dominos or walking and holding someone's hand, but they can't do this with him because the staff don't have time for one-to-ones.*

*The salami-slicing of budgets and means-testing means people get moved from service to service because it's cheaper - there's no personal choice in that.*

## Communication

*Most of the arranging for the care at home service was left to me and I was working blind, told to find my own carers. Where do you start?*

*Organisations want to pass you on a lot of the time, or they only give us partial information.*

*My experience with information services is that there has been too much signposting. There's no point passing us on because we will forget! It is a very mysterious process getting support*

## **Privacy**

*She was once very upset about her case being discussed in an 'open forum' where everyone could hear on the [acute setting]. She was also upset that the hospital approached her family to discuss her care without her present and without asking her.*

*I have my room locked and I have my own key. I like that. Only trouble is sometimes I can't get in!*

## **Dignity and choice**

*Dignity and respect can be confused with choice - so in Care Homes, care is not always given due to refusal by the patient which can lead to neglect. Common sense needs to prevail over showing dignity and respect.*

## **Advocacy (from carers or formal advocates)**

*I think it's immensely important that where people are not able to make their own decisions and they still wish to obviously maintain as much independence as they can, they remain in their own environment. It's important for social services, doctors, whoever is involved with the care of that person to recognise the importance of their family, the closest contact with that person who can represent them and actually be involved with the decisions that are being made.*

*It is not easy to complain as a Carer of someone in Care Home, as you feel that they might take it out on the person in the Home. You feel like you have to tread very carefully. It shouldn't be like this.*

*At the hospital I made a complaint and they just made me feel I was making it all up. It just depressed me, even though I had support from SEAP.*



## Appointment and waiting times

*We had a situation last summer where my daughter had an appointment at the JR at 1.30pm but we didn't get home until late that night. They knew I was a carer so I was frantically trying to call people who could go and look after [my husband]. No consideration or individual care.*

## Recommendations made by participants of groups (direct quotes from patients, service users or carers):

1. In order to respect a person and treat them with dignity, carers need to be fully informed about individual's conditions, what they can and can't do and how they would like to be supported. This information should be easily accessible to new carers. Care staff should be better educated about the condition of the person they care for.
2. Service users are often unable to make choices and have control over their care (one of the Dignity Do's) due to a lack of information about the range of support available. This sometimes results in people not receiving adequate support for extended periods, particularly when coming out of hospital.
3. Carers need to treat service users as a person by listening carefully to their needs and wishes. Carers must get to know the service user and their condition well so that they can assist the service user to express their wishes fully.
4. When care given to people with memory problems make sure that there are no more than 3 people giving the care. Too many people only confuse the people receiving the care.
5. Better support for elderly carers to avoid costly crisis and people needing to go into costly NHS hospitals or care homes
6. A system which allows domiciliary carers to arrive within 10 minutes of scheduled time and which allows for longer than 15 minutes. This is just insufficient. Allow enough time for care and offer housework such as washing for short periods.
7. 'I don't want more dignity - I want better care. You need to increase the fees by around 50%. A shower once a week for those with double incontinence is not enough.'

8. There should be a high standard of care available for all that need it. No battles to access such care. The care should be for the 'whole' person not just immediate physical needs.
9. Clients need time and dignity. People who are being cared for should be treated as you would wish to be treated yourself.
10. Training and skill is so very important but equally so is that staff are caring people. If they are not they are in the wrong occupation

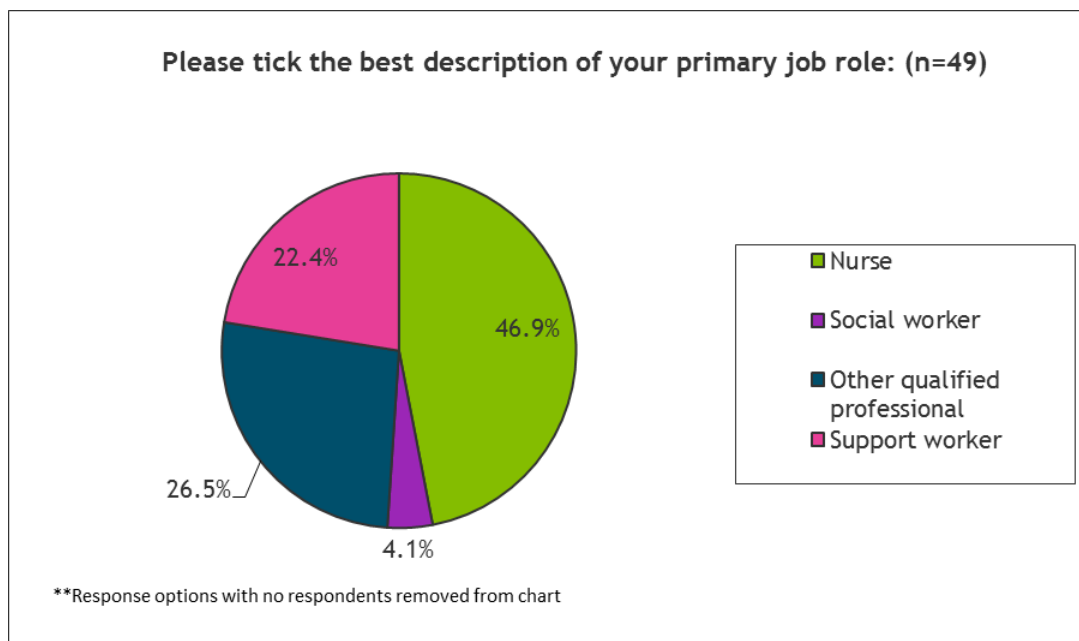
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## 6 Views of health and care staff

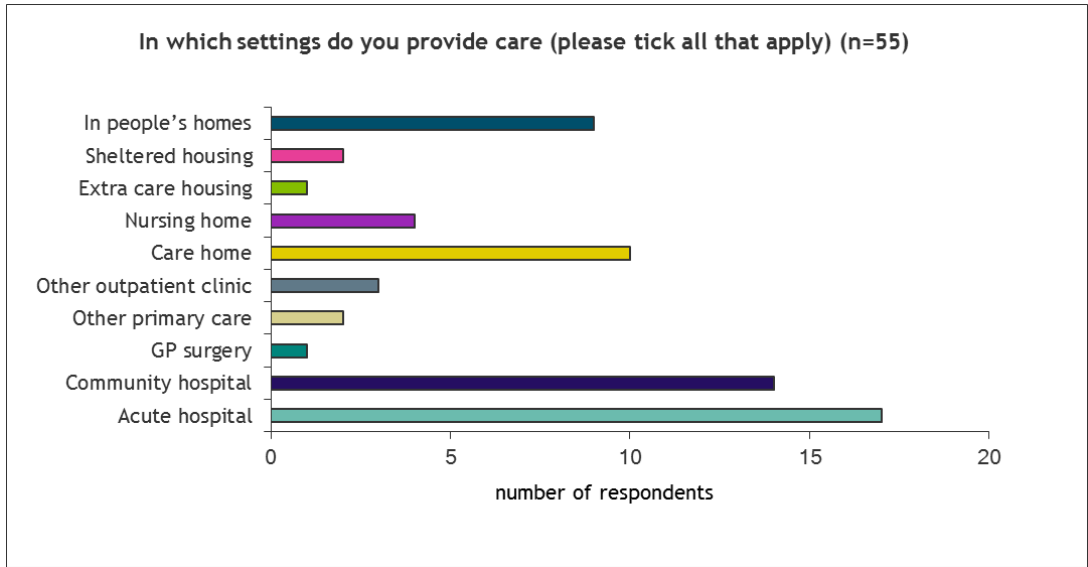
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The staff questionnaire was made available online, and the link advertised through stakeholder groups, and provider organisations. Enter & View volunteers also delivered 5-10 copies to locations where they conducted interviews with a freepost envelope to return them to HWO.

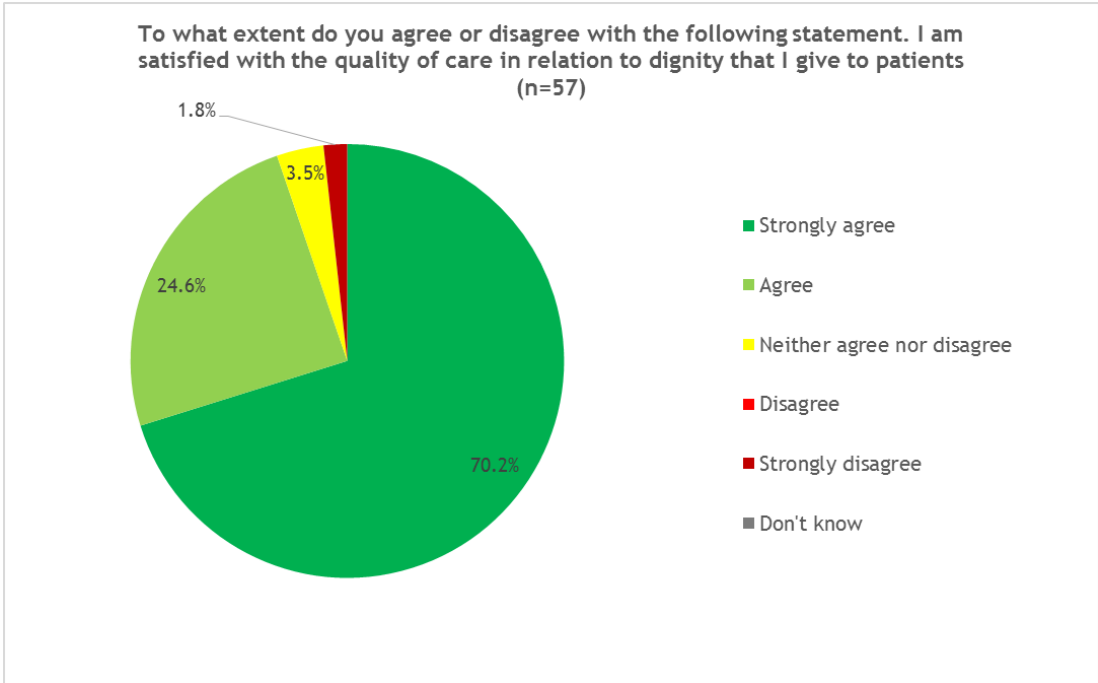
A total of 57 participants completed the staff questionnaire, 46.9% (23) were nurses, 26.5% (13) identified as other qualified professional, 22.4% (11) as support worker and 4.1% (2) as social workers.



The majority of respondents provided care in acute (30.9%) or community (25.5%) hospitals, potentially reflecting those who received hard copies of the questionnaire. There was representation from the community and care sectors with 16.4% (9) respondents providing care in people's homes and 18.2% (10) respondents providing care in care homes.



Staff views on dignity in care are overwhelmingly positive. They show a workforce that is committed to the concept of dignity and that aims to deliver care with dignity. Indeed when asked how satisfied they were with the quality of care, in relation to dignity that they give to patients, 94.7%, or 54 of 57 respondents to the question either 'strongly agreed' or 'agreed' with the statement. Only one participant 'strongly disagreed, and two respondents neither agreed nor disagreed.



Participants were asked to follow up if they disagreed with the above statement, to which the staff member responded:

### *Staffing levels means I do not have time*

This is a theme that crops up within the staff survey, the importance of staffing levels in order to have ‘enough time’ to deliver care in a way that honours the dignity of patients, service-users and their families.

The next section of the staff questionnaire asked the extent to which participants agreed or disagreed with statements about care, and processes within their organisation. On the whole staff were happy to agree with the (positive) statements. This was particularly the case where those statements dealt with broad, or overarching concepts such as, ‘dignity and respect’ or whether they’d be happy with the level of care provided at their organisation for their family.

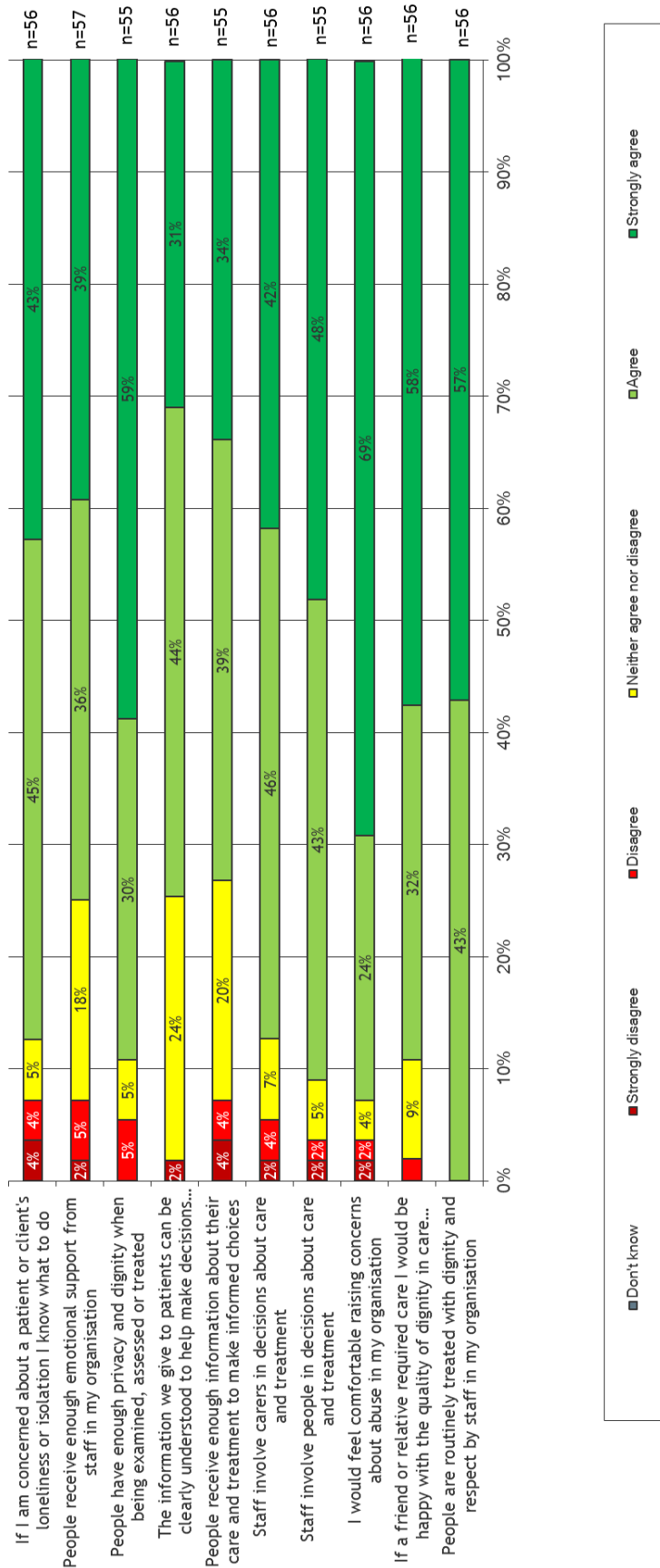
Where statements were more specific, dealing with a particular aspect of care or point of interaction with a patient or service user, a small minority of staff then responded either that they strongly disagreed, disagreed or neither agreed nor disagreed, showing that when dignity is broken down into the ‘Dignity Do’s’ that staff are less confident that their organisations are ‘getting it right’.

One respondent disagreed with the statement “if a friend or relative required care I would be happy with the quality of dignity in care provided by my organisation” with 8.7% (5) neither agreeing nor disagreeing. 4% (2) of respondents disagreed, that they would be able to raise concerns about care in their organisation. On the questions of involvement, 4% (2) disagreed or strongly disagreed that their organisation involved carers appropriately and the same number 4% (2) on whether people were involved in decisions about their care.

Staff were unsure about information giving with 20% (11) neither agreeing nor disagreeing that people received enough information about their care and support to make informed decisions, with 8% (4) disagreeing or disagreeing strongly. Similarly, 24% (13) respondents neither agreed nor disagreed that information given to patients could be clearly understood, with one person disagreeing strongly. 5% (3) of staff disagreed that people received enough privacy while being examined and 6% (4) disagreed or strongly disagreed that people received enough emotional support from staff within their organisation. Finally 8% (4) disagreed or strongly disagreed that they would know what to do if they were concerned about someone’s loneliness or isolation.

Though the numbers are small, it is important to note that not all staff are confident that the elements of dignity within their organisation are being addressed, despite their confidence that overall, dignity and respect are thought to be met within their organisation.

To what extent do you agree or disagree with the following statements



Staff were also asked to respond to two free text questions. The first “what enables you to provide dignity in care to people” and the second “what gets in the way of providing dignity in care”. Many staff very closely linked the concepts of privacy and dignity within comments, perhaps reflecting their organisation’s policies. In some instances, however, staff did seem to use them interchangeably, which begs the question whether notions of dignity amongst staff should be broadened. Two very similar quotes highlight this:

*The correct equipment to be used towels to cover people, doors shut, curtains shut. Knocking on doors and waiting before entering*

*When all equipment is in places making sure curtains and doors are shut when discussing care*

Typical responses to what enables staff include:

*Time, good staffing, space*

*Treat them as I'd like to be treated. Talk to them as I'd like to be talked to respect them, listen to them, ensure they understand their care / aspects of their care*

*Allowing patients to say what care they want and how e.g. cleaning themselves*

*Multi-disciplinary teamwork. My own ethics and morals*

*By continuing assessment of physical, mental and emotional needs and to help patients and carer to make informed choice and decision about their care.*

*Good staff training*

*Local Knowledge, information and advice and good relationships with local authorities and external bodies*

*A willingness to listen and act according to patients wishes time to provide care in a way that suits the patient continuity in care provision respect for the individual putting the person first remembering the patient is the expert of their health and LTC partnership in care the patient is the heart of everything I do*



## Typical responses to what gets in the way include:

*As ever, time.*

*Lack of time. staff shortages. competing demands on time. Occasionally individuals who lack skills in empathy*

*Nothing, providing dignity in care is free. People coming in to our care may not remember our names but they always remember how we make them feel. So it is so important to listen and give people time. Even though at times I can be ultra busy and need to be in two places at once, I would never let my patients think I am in a rush..... I never glance at the clock, or say I will be back in a minute.*

*Lack of awareness/ training and poor understanding of people's needs. and understanding of different patient behaviours which are challenging.*

*Time constraints will always be an issue for staff. Having enough time to listen and hear patients views when they are busy is difficult. The geographical area we live in is also a factor in patients feeling lonely and isolated. Being able to access groups etc without transport is an issue. Offering this support therefore is an issue when patients leave the hospital setting. Offering complete privacy can be difficult in ward bays.*

*The hospital I work in strives to put dignity at the top of the agenda when it comes to patient care. However the staffing of this unit makes this challenging at times and working with the 12 hour shifts with, at times no breaks, it isn't surprising that dignity is sometimes compromised - unintentionally.*

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## 7 References

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### About Healthwatch Oxfordshire

Healthwatch Oxfordshire is an independent organisation that listens to your views and experiences of health and social care in Oxfordshire. We work to help you get the best out of these services, whether it's improving them today or helping to shape them for tomorrow. We have the ability to hold health and social care providers to account.

### About Age UK Oxfordshire

Age UK Oxfordshire is an independent local charity working to ensure that carers and older people live life in comfort, with support when they need it and with opportunities to live life to the full. Delivering a wide range of services, including Information & Advice, support for independent living, clubs and classes, befriending and social opportunities, help around the end of life and carers' support, the charity is an active and prominent partner in the Age UK movement.

### Acknowledgements

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# Appendix 1: Case Studies and Focus Group reports.

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We received case studies from groups who had raised a dignity related issue with us in the preceding year including, Age UK, Guideposts Trust, The Asian Women's Group, 'My Life, My Choice' and Headway. We have included them in full text below. Age UK and 'My Life, My Choice' produced video patient stories which can be accessed at:

<http://healthwatchoxfordshire.co.uk/healthwatchoxfordshirereports>. The names have been changed in these case studies and other than removing identifiable information HWO have not edited the case studies.

## Patient Story 1

**Names use are fictitious.**

**Interview took place 30<sup>th</sup> April 2015**

### Background

Amira is currently a carer for her mother in law, Bashira who has severe Alzheimer's disease and has been bedbound for the last 15 years. She (and her husband) provide her personal care. Bashira has been in and out of hospital over many years. The family are Muslim adhering to strict religious and cultural values.

The interview is mainly based around Amira's discussion of two admissions to hospitals for infections. The first is current - Bashira is in the John Radcliffe hospital. Amira mainly refers to ways in which she feels her mother in law has not been respected in terms of her culture religion and privacy. She talks too about the fact that staff are not able to give Bashira personal care and this must be done by the family.

Secondly Amira refers to an incident in the Churchill Hospital and talks about how she left her mother in law overnight coming back in the morning to find that she had not been cleaned or changed, had not eaten or taken her medication. The manager then asked a male nurse to care for Bashira... Amira discusses how this affected Bashira.

### Interview

#### 1. Name

Amira (carer) and Bashira (cared for)

## 2. Which services have you used?

Throughout the time that Bashira has been unwell she has used a number of services. The hospitals mentioned are The John Radcliffe and The Churchill.

## 3. Do you feel you have been treated respectfully by all the people involved in your care?

Amira reported that Bashira had not been treated with respect in the following ways,

### Religious and cultural values disregarded.

As a strict Muslim Bashira has strong values around, privacy, clothing and gender of those caring for her. She noted that Bashira was **left uncovered** as a nurse checked her blood and Amira says *'if she was with it she'd have had a fit'* (covered in question 7). Amira also said that **despite asking for a female nurse on occasions, Bashira was cared for by a male nurse** which she felt compromised her dignity and was disrespectful.

*'...as far as possible when she was well she didn't want a male doctor but you know I'm not requesting that. I'd like ... I've said I'd like a female nurse if that's possible and on occasions I've found a man there...'*

Amira goes on to refer to a specific incident at the Churchill hospital (dealt with in more detail in question 11) when Bashira had been left overnight without any food or care. However after the incident the manager brought a *male nurse* in to clean and change her the following day despite Amira having asked for a female nurse. She says,

*'I felt very upset for her. If she was well she would have had a fit she would really have felt neglected and disrespected...she would have felt nobody cares for her.'*

However it was only after 'crying and just expressing my feelings' to the manager this changed that she felt her mother in law was being treated with respect and dignity.

**The nurses spoke over Bashira whilst she was at the Churchill Hospital being treated for an infection. She said,**

*'They just used to give her stuff and went away...either they were having a conversation if they were caring or changing the sheets between them - so nobody was talking to her they were talking over her. And I said to them (when I was really upset at the Churchill when I was talking to the manager) she's a human you need to talk to her'*

After the complaint to the manager the nurses treated her differently *'...that changed when she went next to the nurse's desk. They would do her hair, keep an eye on her, keep her covered, and respect her'*

The staff are not able to give Bashira any kind of personal care (dealing only with her clinical care). Amira referred to Bashira's current admission to the John Radcliffe Hospital noting that her mother in law needs a fixed routine in order to feel comfortable. Due to a shortage of staff Bashira was not able to be given the personalised care she needed by hospital staff. She said,

*'Before 9 o'clock she's got to be ready for bed otherwise she won't sleep all night she gets very agitated and very uncomfortable....And what was explained to us is (the nurses on the ward said to us) "We can't do that; we can't make any promises because we haven't got the staff to give her fixed care. You are more than welcome to come and do it yourself but we can't do it.'*

**4. When your services were being planned, were your personal preferences taken into account?**

Amira felt that the hospital staff were unable to take Bashira's personal care needs and preferences into account. She thought that this was due to,

*'...time constraints I'll say time constraints. They are so stretched. They've got a ward full. They say that they say so if we spend an hour and a half feeding her the others are going to suffer. So we are quite welcome for you to do it.'*

Amira was not asked about Bashira's religious or personal preferences but had to teach staff what to do by modelling what was religious and culturally appropriate. As a result she felt uncomfortable about this and said that she felt she was imposing on them.

*'Like she was a very sort of strict Muslim woman and she'd like her hair to be covered all the time so that's something I would say to the nurses...'*

*'I would have liked the nurse to sit with me for half an hour and say well Amira how do you care for her? What are the little things she likes? Instead of me feeling like I'm imposing on them.'*

On more than one occasion a male nurse provided personal care despite Amira specifically asking Bashira's preference for a female (covered in question 3).

**5. Were there any communication barriers that prevented you from understanding your care arrangements or what was planned?**

It is clear from the interview that Bashira is unable to communicate her own needs and preferences due to her impairment in cognitive functioning. Amira has had to do this for her and she makes the point that as a fluent English speaker that has been fine. However if she had not been, then communication would have been a problem. She says,

*'And would there have been an interpreter freely available to interpret that? And then how they explain things could be a barrier and received in a different way. If it's not clearly received. So I think that's a big issue as well. If someone comes in- for example if I had a carer that couldn't speak the language - then I'd expect an interpreter there that could understand it. And not using family members as interpreters because confidentiality always gets compromised when you use family members. And how do you know that they are not imposing their own, they are not saying it from themselves'.*

#### **6. Whilst receiving care were you able to retain maximum level of independence and control?**

Although this question was not answered directly it is evident that **Bashira retained very little control over her own care** for two reasons. Firstly she was **unable to communicate her own needs** and secondly as pointed out by Amira the **staff had no time**. In talking about Bashira's current care in the John Radcliffe Hospital she said only way to control the time of that Amira's medication and ensure personal care was for Amira administer it herself (see question 4).

*'So what we explained to the hospital right from the beginning - this is her care, you've got to be really careful how you care for her because on hospital wards there's no fixed time when the nurses are free they do stuff but with her you've got to have a fixed routine. Before 9 o'clock she's got to be ready for bed otherwise she won't sleep all night she gets very agitated and very uncomfortable....And what was explained to us is (the nurses on the ward said to us)*

*'We can't do that; we can't make any promises because we haven't got the staff to give her fixed care. You are more than welcome to come and do it yourself but we can't do it.'*

Again Amira was unable to retain control around the gender of the nurse and it was only after she complained that this changed.

#### **7. Did the care you received help you to feel good about yourself?**

Due to Bashira's impairment in cognitive functioning Amira is unclear about how Bashira feels about the care she received,

On one hand she says that Bashira appeared depressed after the lack of care and respect shown to her after in the Churchill and that she knows when she's not respected

*'I found her so upset that day and so depressed that day and I looked at her face and I thought oh you poor thing. But all that changed when she went next to the nurse's desk. They would do her hair, keep an eye on her,*

*keep her covered, and respect her. I think even at that stage they require a lot of respect. Although she's not with it I know that she knows when she's not respected.'*

When the nurses began to talk to Bashira rather than over her Amira says, '*..she (the nurse) would talk to her and she (Bashira) was so happy*'.

Conversely when Amira was asked later on in the interview if Bashira knew what was happening (in terms of the care she was getting) she said,

*'Her Alzheimer's is so severe she is not aware of it.'*

What is clear that if she was well she would have felt very strongly about being disrespected and her needs not being met, as do her family. . See Amira's comments below

- On being left uncovered

*'If she was 'with it' she would have had a fit'*

- On being cleaned by a male nurse

*'She's got Alzheimer's I don't know how she would have felt at the time. I felt very upset for her. If she was well she would have had a fit she would really have felt neglected and disrespected. She would have felt very neglected and she would have felt nobody cares for her'*

- On lack of personal care (Churchill Hospital)

*'She would be really upset if she knew this was happening to her.'*

8. **How have your relatives or carers been involved in decisions that affect your care, and have you been offered appropriate support?**

Amira did not talk about the decisions around clinical care but it is clear from what has been said before that she felt that she had been disregarded when she had tried to give instructions (on Bashira's behalf) about medication and personal preferences (religious and cultural sensitivity)

9. **Has your privacy been respected appropriately?**

Amira reported that this had not been the case when Bashira had been left uncovered,

*'so she wouldn't like to be uncovered at any time and once I walked in and she was half uncovered. Someone came to check her blood test or whatever; because she just wears a gown and no trousers you could see her legs'*

As well as this she felt that her right to have private space was not respected as Bashira had been in a mixed ward.

10. **Did your care needs every make you feel lonely and if so did the people providing your care understand this and help you find ways to overcome it?**



Amira said that she felt Bashira was lonely,

*'I think at time (she) feels lonely because no one understands her care..its a very lonely place to be..in bed and be ill''*

#### **11. Have you witnessed any bad experience or abuse?**

Amira went into detail about one specific example of neglect in the Churchill Hospital. Bashira went in to the hospital in the afternoon and Amira spoke at length to staff about what she needed-medication, feeding and personal- care however when she got there this is what she found,

*'So me and my husband went there next day at lunch time and we found...what we found is..the evening pills were still sat there. She hadn't been turned in the night she...the morning pills were still sat there the breakfast was just dumped on the table. She hadn't had anything to eat and she was soaked, dirty so I actually had a fit. I said look this is not on. I went through all this in the evening. She's not been turned she's just been left there haven't they. I felt that ever since I've left her nobody's come back to check on her. She's not even been given a drink to the next lunch time.'*

*'...What I was saying to him was - I'm taking her home. I care for her (at) home more than she's cared for in hospital basically it looks like you haven't done a damn thing for her I'm going to take her.'*

After this the manager did apologise, however as noted in previous answers he sent a male nurse to care for Bashira. Amira's response is as follows,

*'I said well actually I've been through this she don't need a man here. We don't use a man she's never ever you know, very private woman. She wouldn't want a man to clean her.... so I had to step in and do all that myself.'*

Amira clearly documents this incident of neglect which the manager apologises and tries to make amends. However this is inappropriate as he did so by sending in a male nurse which Amira finds unacceptable on religious/cultural grounds. She had no choice but to care for her mother in law herself.

#### **11. If you wanted to give feedback, good or bad, about your own care did you know how to do that? If you wanted to complain were you supported to do so?**

Amira responded to this question by referring to the above incident at the Churchill where she complained to the manager. She says that she spoke to the manager but she didn't know where she could take it beyond that,

*' I didn't do any more than that I just spoke to the manager and I was so glad to get her home and um you know to be honest I didn't know where to take it above that but I thought by talking to the manager I'd hope he'd get the message...'*

When asked if she wanted to take it any further or if she would you have known how to do that she said *'At the time I didn't know but if I would*

*have known I would have'. However things did change as a result of her speaking to the manager.*

**12. Which of the Dignity Do's do you think are most important? (list your top 3)**

Amira reported that 3,6, and 7 were the most important. Her comments are noted below.

**Treat each person as an individual**

*'I think the most important thing is respecting the person for who they are. Respecting their culture, respecting their religious needs respecting their family needs. I know that they can't meet everyone's needs but at least understanding that this is their needs...'*

*'...That's what needs to happen-they need to spend that time. Have a separate ward for high level care need people and then they provide care according to the culture religion, the personality of the person'*

**Respecting Right to privacy**

*' I think respecting rights to privacy is an important one.. um you know ensuring that people feel able to complain. I do feel that when I go into a hospital or a service like that with her I feel like I'm pushing the boundaries all the time. It feels in a sense- I feel that we are sort of asking for too much. You know the way the staff talk to you, you know you've got a care service here.'*

**Complaining without fear of retribution**

*'um you know ensuring that people feel able to complain. I do feel that when I go into a hospital or a service like that with her I feel like I'm pushing the boundaries all the time. It feels in a sense- I feel that we are sort of asking for too much.'*

**13. Can you tell us anything really good about the care you received in Oxfordshire? (**

It seems that for Amira good care represented Bashira **being treated as a person** responding to what was important to her and taking into account her cultural, religious, family values and preferences.

Amira uses the incident at the Churchill Hospital (after changes had been made) to highlight this,

*'They kept her head covered for example. It was really important to her. Her legs were always covered with a blanket or something. Really important to her. Not having short sleeved gowns which was really important to her. You know all these little things. And she was clean, her hair would be combed. She was a very proud and tidy woman when she was well. So that means a lot sort of her presentation*

*even at that age was really important to her. So that was sort of ...really meant to her that was done? I know its little things but I used to look for those. Is she covered? Is her arms covered? Has she got a scarf on, um, is she well kept? Is her hair been combed? Has her face been cleaned? You know those little things. Has her hand been cleaned. That's what you know that's her when she was well.'*

## Patient Story 2

### 1. Name ...Aliya

I am a [age] Pakistani woman and cannot speak, read or write English I can only speak my language Punjabi. I have three children who care for me at home because I have [long term health conditions] that affects my mobility

### 2. Which services have you used

I use my GP, Hospital and health clinics

### 3. Do you feel you have been treated respectfully by all the people involved in your care?

I was admitted in to hospital for a [procedure]. My son was with me before I went in to the operating theatre so I felt safe.

My son had expressed for a woman nurse to look after me but from time to time a man would come and check me. In the evening a male nurse came to change my bed I refused and said no but still he helped me out on to the sofa and fixed my bed.

I was so embarrassed and upset felt so alone and helpless because I was not listen to and I was not respected.

### 4. When your services were being planned, were your personal preferences taken into account?

I don't know because my sons talk to the doctor, I don't know the details of it.

### 5. Were there any communication barriers that prevented you from understanding your care arrangements or what was planned?

After the operation when I came round I was alone and felt so helpless because I wanted to explain to the nurses that I think my blood sugar is going down and I need something sweet but I couldn't communicate and

the nurses did not ring my son or make an effort to get an interpreter. I was shaking and feeling weak.

6. Whilst receiving care were you able to retain maximum level of independence and control?

I felt totally out of control and was looking at the professionals to help me out. Most of all I was looking out for my sons. I was so frustrated because I felt I didn't have a choice in anything.

7. Did the care you receive help you to feel good about yourself?

During the night I became unconscious and was taken to A&E at the John Radcliff hospital in an ambulance with two nurses. When I came round there were tubes and pipes everywhere. I felt so scared and said what happened but of course they didn't understand my language.

My sons arrived shortly after I came round and said that my sugar levels dropped to a dangerous level and something happened to my blood pressure. I kept saying I was trying to tell them but the nurses didn't understand or listen.

I was in the John Radcliff hospital for week then taken back to the Churchill for recovery. I felt so powerless and vulnerable I was so depressed in hospital.

8. How have your relatives or carers been involved in decisions that affect your care, and have you been offered appropriate support?

I wanted my sons to be involved but at times felt that even they did not explain fully what was happening. I do not think I was given the full information before my operation had I known what was going to happen I would not have gone ahead.

I feel that sometimes my sons feel they know what's best for my health and feel I don't have any say.

9. Has your privacy been respected appropriately?

10.

Yes staff did ask and wait for my response before entering.

11. Did your care needs ever make you feel lonely and if so did the people providing your care understand this and help you find ways to overcome it?

I felt very lonely at the beginning of my care, and after the incident, then the nurses allowed one of my family members to be with me so I could feel comfortable.

12. Have you experienced or witnessed any bad treatment or abuse?

13. If you wanted to give feedback, good or bad, about your own care did you know how to do that? If you wanted to complain were you supported to do so?

My sons verbally a made a complain but not a formal complain to be honest they did not understand it

14. Can you tell us anything really good about the care you received in Oxfordshire?

The care improved after the incident and the nurses were much more understanding of my needs such as I had a woman nurse all the time.

They were sensitive to my religious needs by not entering my room when I was praying.

15. Can you tell what needs to change?

The system needs to change by more staff on wards, more staff training on how to treat people like humans rather that a statistic on the paper because we are all human regardless of any culture religion or language.

I think we need to go back to the basics of caring rather than tick boxing all the time.

My top three is Listening, respecting and treat others as you would like to be treated yourself.

### Patient Story 3

#### Section 2: Questions and prompts for shaping your story

1. Name: Alisha

Alisha is a carer for her father in law. He was 74 year old with severe Alzheimer's disease and was cared for at home.

2. Which services have you used?

I can't remember the agency that used to come out and carer for my father in law because it was arranged through social services.

3. Do you feel you have been treated respectfully by all the people involved in your care?

We lived in a very crowded three bedroom house with my other two brothers and sister in laws and my mother in law and three under-fives, lack of space meant that my father in law was living in the living room. The carers came in twice a day to cleanse, change and help bath my

father in law and were very respectful of his condition and the family situation. They would smile and talk to him as if he understood and share a joke with him, he would respond with a smile and felt comfortable with female carers. They respected his wishes when he refused to have a bath and listen to his and the families concerns.

They would ask when it was convenient and if there is anything that they needed to be aware off on a daily basis. They became a part of our family.

When your services were being planned, were your personal preferences taken into account?

A social worker from Manzil way came and explained everything with us. He planned a package with us and gave us several choices to which one we thought would best suit us.

4. Were there any communication barriers that prevented you from understanding your care arrangements or what was planned?

My father in law could not understand or speak English but we communicated for our mother in law who would make the main decisions for him.

Although their were language barriers the carers manage to communicate with my mother in law through body language and pictures.

5. Whilst receiving care were you able to retain maximum level of independence and control?

He was cared for at home and did not mind female carers.

6. Did the care you receive help you to feel good about yourself?

7. How have your relatives or carers been involved in decisions that affect your care, and have you been offered appropriate support?
8. Has your privacy been respected appropriately?

Yes at all times

9. Did your care needs every make you feel lonely and if so did the people providing your care understand this and help you find ways to overcome it?

He must of felt lonely but the carers made him feel good

10. Have you experienced or witnessed any bad treatment or abuse?

No

11. If you wanted to give feedback, good or bad, about your own care did you know how to do that? If you wanted to complain were you supported to do so?

No

12. Which of the Dignity Do's do you think are most important? (list your top 3)

Respect. Listening and genuine caring.

Finally to summarize

13. Can you tell us anything really good about the care you received in Oxfordshire?

14.

I am really happy about our care it was respectful dignifying and delivered with a smile.

15. Can you tell what needs to change?

## Patient Story 4

### G's story

G is a white British female, aged 38 years old. She uses care agencies (these have changed over time and have included Day and Night, Home Helpers and OPC) to provide her with personal assistants to assist her with daily living such as shopping, cooking and cleaning. She also attends Headway Oxfordshire and has support from Community Support Workers at Headway Oxfordshire to deal with her finances and attend meetings.

She feels that generally she is treated with respect by the services she uses, but has had some bad experiences with staff who don't listen to or understand her. Examples of this are below:

1. 'Some of the Day and Night agency staff always seemed like they were in a rush and made me feel like I was a hassle. I was in a lot of pain and wanted to just have a wash in the living room rather than have a full shower in the bathroom but they didn't listen and made me go into the bathroom which hurt a lot. One staff member really upset me by yanking me out of the chair, pulling my dressing gown off and calling me 'unclean' when actually I was in too much pain to have a wash. Lots of the staff don't understand my condition (trigeminal neuralgia) and the levels of pain I have'.

2. 'OPC agency sent in a lot of different staff every day, which I found very difficult because I can't remember names. They sometimes didn't remind me to take my medication. They didn't help me with the housework when they had time over at the end of the shift. They also kept forgetting to leave me a tea plate, which meant that I had to go long periods without any food. I complained to the manager and they then sent in fewer staff and put up post-it notes to remind the staff what they needed to do'.
3. 'One agency sent staff who did not speak very good English. As I have difficulties in communicating due to my brain injury this was very stressful for me'.
4. 'Often I do not get a choice about what to eat for breakfast, they just put the same thing in front of me every day. Although I have stated my preferred times for support in my care plan, in reality this varies widely so my morning support can be any time from 6.45 am to 11 am, which I don't like.'
5. 'With one agency who supported me there was a safeguarding issue with me and one staff member. My social worker decided to cancel my care with them and use another agency. I am not happy about that because I really liked them and they supported me in all sorts of ways that the other agencies don't, for example taking me out, doing baking with me'.

G gave two examples of support she has received that she feels made her feel she was respected:

1. 'Headway Oxfordshire have really helped me to regain my confidence in socialising and in going out places. They give me goals to work towards that I can achieve and I feel good when I have managed to do something new. They really understand my condition and how it affects me and my family'.
2. OPC staff were brilliant people. They listened to me and knew what to say and what not to say. They dealt with difficult situations with me and my family sensitively'.

## Patient Story 5

### S's story

S is a white British female, 48 years old. She uses Headway Oxfordshire services and has had several stays at the Horton and John Radcliffe hospitals because of her brain injury. She has only recently been allocated a social



worker (1 year after discharge) and is hoping to get more support to cope with her brain injury and re-learn skills.

S said she had some negative experiences in hospital. This included being at risk of cross infection due to poor hygiene on the ward (there was someone else's blood on the chair by her bed). She was once very upset about her case being discussed in an 'open forum' where everyone could hear on the A and E ward. She was also upset that the hospital approached her family to discuss her care without her present and without asking her. She was discharged from hospital without any transport to get home and without any support in place.

S said that Headway Oxfordshire has always supported her with dignity and respect. When she was at her lowest point and everything seemed like an uphill battle they helped by setting small goals and making sure she had lots of 'little breakthroughs'. They helped her to get organised in her paperwork and to get her finances sorted. She said they understand her brain injury and how to use behavioural techniques to handle her moods and problems.

## Patient Story 6

D

D is white British and is 44 years old. He uses Headway Oxfordshire services and has support from personal assistants to assist him with daily living such as shopping, cooking and cleaning. He has used two other care agencies.

He said that he is unsure that staff always respect his confidentiality and he worries that care staff may share information about him without his permission, eg to social workers. He is unsure what the rules are on this.

D has had some experiences of care staff making him feel unvalued, in some cases this has made him feel angry and to 'lose it' with them (become angry and verbally abusive). One staff member was spending a lot of time on the phone when she should have been supporting him. Another staff member did not know what was on his care plan and how to support him, leading to her doing things for him that he could do himself and inappropriately giving him personal care in the shower. One agency kept sending staff earlier and earlier, resulting in him missing his support because he was not up. He said he gets fed up when there are rapid changes of carers because he doesn't get to know and trust people. He has complained about this to the agency but nothing has changed.

D said he is happy with his care plan because it came from his own ideas and his dad was involved in setting it up with him. His social worker listened to him and understood what he needs.

## Patient Story 7

### A difficult journey through public healthcare system

#### Introduction

This Patient Story was completed by Guideposts Trust on behalf of the 'Dignity in Care' project which is run jointly by Healthwatch Oxfordshire and Age UK Oxfordshire in 2015. The Patient Story takes us through a range of experiences that the interviewee as had over the past year.

#### About Interviewee

The individual attended a focus group which was also held for the project, and wished to share the extent of his experiences as a carer, navigating his way through uncaring statutory dementia care services in Oxfordshire. He chose to offer his comments anonymously. For the purposes of this Patient Story they will be referred to as LB. His wife, the patient, is referred to as JB.

#### Challenges

##### 1. Which services have you used?

LB and JB accessed a number of services as part of their journey through the public healthcare system, including:

- Accident and Emergency
- Minor Injuries Unit
- Memory Clinic
- PALS
- Alzheimer's Society
- Neurology
- Neuroradiology

##### 2. Do you feel you have been treated respectfully by the people involved in your wife's care?

February 2015 LB and JB attended the Memory clinic for an appointment. After waiting for one hour, LB and JB were seen. JB presented with an arm in a sling and an evident degree of distress and confusion due to her condition and whereabouts. LB felt the Dr acted as if she "just wanted to get home". Without looking to the patient's condition or notes with any level of detail, the Dr stated "I'll not bother to give JB any tests, and it doesn't seem worth you coming back in 6 months - how about 9?" With

evident anger and sarcasm, LB suggested: “why not make it a year?” to which the Dr responded “yes” enthusiastically.

Following this appointment LB had a conversation with member of staff representing the Alzheimer’s Society. The impression given by staff is that they want to help carers, but the individual gave the very opposite impression from the way she spoke to LB: “After seven years of no sleep I had huge bags under my eyes. I need to be looked after too.”

LB’s prevailing feeling on leaving this appointment was: “why am I there?” He felt that staff wanted them out of the building as quickly as possible and that they cared not at all about his or his wife’s welfare.

### **3. When services were being planned, were your personal preferences taken into account?**

JB was placed in a Care Home following the decision in March 2015 that she was no longer able to remain at home in LB’s full time care. LB’s daughter arrived at the Care Home for a visit in April 2015. Upon arrival, the attending nurse was performing a medical examination of JB. She went on to recommend a whole host of issues relating to her health. LB only happened to be involved third party due to hearing about it from his daughter. He had not been invited to attend, or even informed that it was taking place. He feels that things are “not being done with the right people consulted” - namely himself in his role as carer.

Since that list of recommendations was made, LB has had to forcefully chase up on the actions, and strongly feels that if he had not done so none of the recommended additions to care would have been actioned.

This experience brought up questions for LB about his interactions with services over the last 7 years, for instance: “why hadn’t any of these issues been picked up on when they were attending appointments?” His summary of the situation was: “it grieves me that they so consistently don’t get it right; they don’t even try to get it right.”

Alarmingly, LB suspects but cannot prove that the majority of the health conditions listed on this recent document have proliferated as a result of the neglectful care his wife has received in the last 7 years, which has included experimentation with the use of drugs which even qualified staff do not seem confident in administering. “JB is damaged goods now, and whether or not it was them who did this to her I cannot prove. A lone person in this minefield of a system would be lost.”

### **4. Were there any communication barriers that prevented you from understanding your wife’s care arrangements?**

In December 2014 LB cut her lip badly after a fall. JB and LB went to a Minor Injuries unit. Here they were advised that the unit was ill-equipped to deal with the injury and were referred instead to A&E. After the standard two hour wait they were attended by a nurse. It was clear to LB that the nurse (recruited from overseas) could not understand what LB and JB were saying, and equally they could not understand him. This made for an incredibly frustrating conclusion to an already lengthy (and unresolved) attempt to access public health services.

**5. Whilst receiving care were you able to retain maximum level of independence and control?**

Continuing on from the experience shared above, LB and his wife were referred on to yet another clinic about her lip the next day. LB was exasperated that the journey towards receiving care had been so unwieldy: “Why couldn’t the Doctor at the Minor Injuries unit agree a solution, or think to themselves: ‘what is the best route for a person in light of their condition?’”

**6. If you wanted to complain about your wife’s care were you supported to do so?**

Facilitating the process of making a complaint and seeing this fail to be followed through was a further source of great disappointment for LB: ‘You can say what you like but nothing comes of it.’ Following the experience at A&E in December 2014, LB went to PALS department on the day to file a complaint. One month on and LB had heard nothing about the progress of his complaint. He then followed up with a phone call to the PALS department; where he was informed they had “forgotten” to process his complaint. Feeling incredibly frustrated by this, LB then took the initiative to phone the Head of PALS. LB summarised his experience and was informed by telephone that: “we can’t do anything unless it’s a formal complaint.” As such LB requested that this be listed as such. This telephone conversation took place in January 2015 and now, months later he is still yet to hear anything about whether his complaint has been carried through.

For LB and all he and his wife have been through in the last 7 years, this final blow was very difficult to take. “It’s all about communication. They don’t look for the straightforward way out. It’s just not a caring profession anymore.”

**Summary**

It is evident that LB and JB have encountered a great deal of challenges, and case examples provided from just the past twelve months give a clear picture of the lack of dignity that is inherent in communications between the couple and various public health departments within NHS.

## Focus Group 1



### DIGNITY IN CARE

#### Focus Groups with Carers

This material has been gathered through talking to older Carers from three groups.

#### Confidentiality and anonymity

Anonymity was requested by participants in most instances.

Two Oxford Care Homes, were highly praised, as was a home-based care service.

#### 1. Which services have you used?

Care Homes (10 people), Day Care (2 people), Hospitals (4 people), care at home (5 people). NB. Some participants referred to more than 1 service.

#### 2. Which of the Dignity Do's are most important to you and why?

Different Dignity Do's were important to different individuals, with no clear pattern emerging. Many found it hard to choose one above another, as they felt most of them were equally important and, that for people to feel their dignity is being respected, all ten should come into play (as intended by the Charter).

Having said that, the Dignity Do's listed below were deemed the most important, with the first being highest rated by the most participants:

- Have a zero tolerance of all forms of abuse.
- Support people with the same respect you would want for a member of your family.
- Treat each person as an individual by offering a personalised service.
- Enable people to maintain the maximum possible level of independence, choice and control.
- Listen and support people to express their needs and wants.
- Ensure people feel able to complain without fear of retribution.
- Assist people to maintain confidence and positive self-esteem.

- Act to alleviate people's loneliness and isolation.

### 3. Do you feel you have been treated respectfully by all the people involved in your care?

A mixture of responses, as to be expected:

- *Yes definitely, all the services received in the [Care Home] were very professionally given.*
- *Although a person cared for in her own home reported that Social Services carers couldn't have done enough for her, her neighbour carers had mixed responses to the service mainly owing to: 15 minutes not being enough time, never knowing what time the carers would arrive and having so many different carers in very few days, so not being able to build continuity or trust. 'The carers have all, in themselves, been very caring and charming but frustrated by the system they find themselves in because they want to care for people well and to be able to spend more time with them.'*
- *Dignity and respect can be confused with choice - so in Care Homes, care is not always given due to refusal by the patient which can lead to neglect. Common sense needs to prevail over showing dignity and respect.*
- *Most of the arranging for the care at home service was left to me and I was working blind, told to find my own carers. Where do you start?*
- *In the [Nursing Homes] the care is often not good enough. More back up is always needed.*
- *My son has severe learning difficulties and little speech but he has always been treated with dignity and respect at [Day Centre].*
- *I think the care package from the adult mental health team is insufficient.*
- *The carers that visit my aunt at home, through Social Services, often don't have enough time to do what they need to do. Two days running she didn't have her tablets, and they had to leave them beside her and she didn't take them.*
- *Although the care we had, through District Nurses, was brilliant you can't get the same one all the time, you get one at one time and one at the next and you can't build a rapport with them.*
- *For the majority of the time, care at [Care Home] is excellent and as if those receiving care were much loved family members. Lapses occur when 'respect' triumphs over the need to deliver the necessary care. This has been addressed in the [hospital]. The medical care was excellent and the staff were working very hard but the level of care on [ward] is inadequate for those with dementia-which appeared to be the majority. I understand that the ward is due to be remodelled*

*and dementia awareness has increased. The food quality was dire and would not promote speedy discharge*

- *It's impossible for Carers doing 20 minute home visits to shower someone, dress them, give them their breakfast and their medication. I can't even do that for myself.*

#### **4. When your services were being planned, were your personal preferences taken into account?**

*This was excellent in the [Care Home].*

*In the case of people with a dementia, it is hugely important that the Carer's voice is heard. 'This is a farce my husband is not able to express preference or choose and yet he is continually offered verbal or written choices. This is a nonsense and best interest decisions need to be made for him.'*

*At the [Day Centre], we are always asked what we want to do and as far as possible are given that choice*

*With domiciliary care, I constantly had to argue my case. Care plans took forever to come through. This caused a great deal of distress*

*At the [Day Centre] service planning is good with a Care Plan at both the [Day Service Centre] and also the [Respite Unit].*

*To the best of my knowledge my son is always asked what he prefers to do even though it is difficult. Staff do put a lot of time into making sure my son understands.*

*I asked what care I could get when first out of hospital but was told the hospital would sort this out. But care for my husband was only for the time I was in hospital. I came home and had to cope. There is no joined up thinking.*

*I was told care for my husband with memory problems was different from care I would need. This was nonsense as I would need help to prepare meals, do washing for both of us. We were treated as different cases in the same house. Madness!*

#### **5. Were there any communication barriers that prevented you from understanding your care arrangements or what was planned?**

*Yes, but not because of languages or other specialist requirements - I found my own carers for my relative at home with memory problems but wasn't able to tell them what they were going to be paid. I didn't understand the system, no one explained or seemed to have the time to explain.*

**6. Whilst receiving care were you able to retain maximum level of independence and control?**

*We had an incident where antibiotics needed to be given 4 times a day, a carer goes in 3 times a day but the medication has to be given on an empty stomach between meals. So it required a group of us to actually organise a rota, so that the appropriate medication was given at the appropriate time.*

*This is complicated when it comes to someone with dementia. The need for retaining maximum level of independence and control is often used as a reason not to give sufficient care.*

*Yes some of the time but it is not always possible to go with choice due to staffing issues at the [Day Centre] which will only get worse if the [Day Centre] closes. This would mean being in the family home most of the time with a small personal budget which would not purchase a full week's daytime care.*

**7. Did the care you receive help you to feel good about yourself? How? If not, what happened that made you feel depressed or powerless, or that knocked your confidence?**

*Yes always. The [Care Home] staff were very good at helping people in this way.*

*There are not enough activities at [care home] or enough care staff, which of course affects how people feel about themselves. This is driven by OCC capping the fees at an unsustainable level. The motivation of the staff and management are excellent but their budget is insufficient.*

*With the Care we receive at home, as a carer I have been made not to feel good about myself. I feel I am criticised for making complaints.*

*At the [Day Centre] people are encouraged to do new things like cooking, which helps you feel good about yourself.*

**8. How have your relatives or carers been involved in decisions that affect your care, and have you been offered appropriate support?**

*I think it's immensely important that where people are not able to make their own decisions and they still wish to obviously maintain as much independence as they can, they remain in their own environment. It's important for social services, doctors, whoever is involved with the care of that person to recognise the importance of their family, the closest contact with that person who can represent them and actually be involved with the*



*decisions that are being made. I did not feel that I was listened to by Social Workers in a Community Care Assessment meeting and was made to feel like I was interfering, even though I am extremely familiar with the needs of this older person who now has dementia.*

*As a carer, I always felt involved at all levels, the [Care Home] did this very well.*

*My care providers identified people who they involved in my care without asking me first.*

*At the [Day Centre] this is done very well. Those who we wanted were involved appropriately throughout the care and annual reviews held with chosen family members.*

**9. Has your privacy been respected appropriately?**

*Yes, in the [Care Home].*

*Crazy tick boxes and draft policies mean that care and common sense go out the window. Privacy meant taking my husband to the toilet and then leaving him alone in the cubicle.*

**10. Did your care needs ever make you feel lonely and if so did the people providing your care understand this and help you find ways to overcome it?**

*My husband who has dementia, often shows signs of agitation and needs more one to one attention than is available.*

*When you see a loved one not being looked after well, and them feeling alone, you often feel a failure yourself as a carer. It would be good to have one person you could talk to about what you are going through on a daily basis as a carer.*

*Not at the moment but that could happen if the [Day Centre] closes and my son is unable to meet with his friends and be stuck at home with nobody to take him to the activities which he enjoys.*

**11. Do you experience or witness any bad treatment or abuse?**

*Yes, at [Care Home]. The Social Worker thought that safeguarding only applied to those that were social services funded. [Care home] should have been closed down. Staff were brought in from [outside County] to cover when inspections were made.*

*I reported abuse to staff but it was difficult because they were from an agency, where the turnover was so high,*

*I felt at times my aunt is neglected at the care home she is in. For example, her drink would be propped up on her blanket, with a biscuit on her shoulder. She can only use one finger and thumb on left hand. She needs feeding and is frail now. She is fed yogurt although I have told them she hates it.*

**12 .If you wanted to give feedback, good or bad, did you know how to do that? If you wanted to complain were you supported to do so?**

*The whole culture in the home was dire. I spoke to Safeguarding and to the Care Quality Commission. Their response was totally inadequate.*

*It is not easy to complain as a Carer of someone in a Care Home, as you feel that they might take it out on the person in the Home. You feel like you have to tread very carefully. It shouldn't be like this.*

*At [care home] I felt I was able to make a complaint, but whilst my husband was at [other care home] I felt that if I made a complaint I would put my husband at even greater risk.*

*I think it depends on the nature of the complaint.*

*At the hospital I made a complaint and they just made me feel I was making it all up. It just depressed me, even though I had support from [advocacy organisation].*

*I am worried about complaining because sometimes we are not there and I feel it might make it worse for her.*

**12. Can you as group highlight up to 3 really good things about care in Oxfordshire?**

The care staff:

*'The love given by carers'*

*'They notice when my husband is out of sorts. They care about him as well as for him. They treat everyone as individuals. '*

*'The person I found to care for my husband when I was in hospital was so kind and it worked well.'*

*'With my aunt in the nursing home the staff that were with her were excellent but they often left due to working conditions.'*

*'Day centre staff take me to the activities I enjoy - swimming horse riding, outings. Day Centre care is really good at [day centre]. Everyone is so*

*friendly and I enjoy the activities. The respite staff are so welcoming and friendly and I really enjoy going there.'*

**13. Can you as a group suggest up to three things that Healthwatch Oxfordshire and Age UK Oxfordshire should lobby/campaign for to improve services?**

*When care is given to people with memory problems make sure that there are no more than 3 people giving the care. Too many people only confuse the people receiving the care.*

*Better support for elderly carers to avoid costly crisis and people needing to go into costly NHS hospitals or care homes*

*A system which allows domiciliary carers to arrive within 10 minutes of scheduled time and which allows for longer than 15 minutes. This is just insufficient. Allow enough time for care and offer housework such as washing for short periods.*

*'I don't want more dignity - I want better care. You need to increase the fees by around 50%. A shower once a week for those with double incontinence is not enough.'*

*There should be a high standard of care available for all that need it. No battles to access such care. The care should be for the 'whole' person not just immediate physical needs.*

*Clients need time and dignity. People who are being cared for should be treated as you would wish to be treated yourself.*

*Training and skill is so very important but equally so is that staff are caring people. If they are not they are in the wrong occupation.*

**Extract from recording, Carer of a neighbour with dementia.**

*'She has dementia and was admitted to hospital with an infection which was increasing her confusion and making life more difficult for her. She was kept in the [hospital] for 6 weeks and she was actually going ballistic because it was a completely alien environment, completely and unable to actually make rational decisions and the hospital was making it much, much worse. She couldn't relate to that environment and she was moved from one ward to another, and it took a long time to actually get out. Obviously the hospital wanted to discharge her but she was insistent she wanted to remain in that home, she had lived there 91 years, she had parents in that*

home who had passed away in that house and that was it, she was going to stay there. At the end of last year, she wanted to make her will and she wanted to organise her life. She was rational enough to do that, and there was an assessment on her mental faculties to show that she was able to make some decisions, even though on the day to day she couldn't remember whether she'd had breakfast, or whether she had taken tablets or whatever.

When she was discharged from hospital there was an assessment the day she went home with an assessor from community care, there was a community social worker, one of the carers from the care company, a community Occupational Therapist and there was me. This lady was completely overwhelmed by so many people, she was angry, she was upset, she was confused and she had just come home from hospital to her own environment and she hadn't met them before apart from me. And they were all there together. And they were trying to assess her in all their different disciplines. There was me trying diplomatically to put the right points across to put something together, would understand what this lady's life had been, and what she needed to get back to in order to settle. And so this situation was very difficult. We tried to facilitate, but I was asked by social services not to interfere as social services/ community care needed to get to know this lady. The following week there were 8 different carers going in anytime between 8-11 in the morning, 12-2 and 6 in the evening. This lady had a very rigid routine. These carers were going in and saying 'have you had your breakfast', not checking whether she actually had. I have witnessed this. Then they said we can't supply meals unless we have a microwave because 20 minutes is our maximum. They were really resistant. So a friend gave them a microwave on long-term loan and left it to the carers to try and negotiate, but then she was getting 2 lunches in one day or not getting fed. Talking to the carers who were trying their best, whose main frustration to them was the lack of understanding, communication and administration and lack of time to spend with each person. They had to rush all around Oxford and spend time travelling. The carers more and more are saying we are going to get out of this job because there is too much pressure and yet they are excellent. You know, many have been trained in dementia care, they know what they are doing, but they are being driven crazy by this system, the lack of real understanding of what they do and how they do it. The administrative side, I really think they have a very lackadaisical approach. If I report something, they don't pass it onto the carers, so you go in the next time and say 'did you know such and such happened or such and such is needed to be done and they say' no, we didn't know' - they haven't been told.

## Focus Group 2



# Healthwatch Oxfordshire ‘Dignity in Care’ Project Oxford Focus Group Notes

### LOCATION

Peace House, Paradise Square, Oxford

### DATE

20/04/2015

### DURATION

1 hr 30 mins

### FACILITATORS

1. Laura O’Sullivan (Guideposts Trust, Project Officer for Service User Communications)
2. Annie Davy (Healthwatch Oxfordshire, Project Fund and Engagement)
3. Claire Ward (Guideposts Trust, Information Services Manager)
4. Jan Cottle (Guideposts Trust, Dementia Information Co-ordinator, Oxfordshire)

### PURPOSE

This focus group was intended to inform the ‘Dignity in Care’ project being led by Healthwatch Oxfordshire and Age UK Oxfordshire, which Guideposts is pleased to be partnering on. Our Dementia Information Support Service (DISS) is a widely-respected and active resource for people living with dementia in Oxfordshire; boasting excellent professional networks, campaigning service user representatives and extensive experience in communicating sensitively with this client group. Furthermore we have a dedicated Project Officer in post who consults with partners on matters relating to engagement and accessible communication. It therefore seemed fitting to assist in carrying out discussions with small groups of people living with dementia to find out if their care has met dignity standards.

### ATTENDEES

There were 5 attendees in total - 2 carers and 3 individuals with a dementia diagnosis. The event had been advertised via social media, emails sent to a selection of current Guideposts service users, via partner organisations and

posters distributed at various sites such as health centres and noticeboards. We were pleased to have a range of attendees, some of whom had had contact with Guideposts in the past and some who were fresh to the service.

## **FORMAT**

As relaxed a format as possible was adopted in the interest of being sensitive to people's experiences and communication challenges. As such following a brief introduction to the project from Annie Davy from Healthwatch Oxfordshire, and a 3 minute film on dignity, attendees were split into 2 smaller groups with 2 facilitators per group. Visual aids were made available on each table representing various themes such as personal care, physical assistance, privacy etc. as well as the list of 'Dignity Do's' and an attendee information sheet. Facilitators had question sheets that could be used to prompt for further discussion if necessary. The two groups briefly came together at the end for conclusion and overview.

## **KEY MESSAGES**

### **1. The need for this report to be used to promote genuine change**

"I don't want another report that sits on a shelf"

"Healthwatch is simply conducting another survey which we have already done before and nothing happened with that"

### **2. Dignity Do's fundamentally absent**

"For me dignity is being neglected. Most of these 'Dignity Do's' point towards practical care needs and from what I have seen, they are all being neglected."

"I have had a series of operations due to stroke. I reacted badly to anaesthetic and so I was completely loopy for 3 months whilst on a ward. I was left for hours in my piss and shit, I was sedated and my health needs were neglected. None of the '10 Do's' were there. It is a completely aspirational list. I have seen no attempts to put it into practice - only lip service."

### **3. Health & Social Care Services under-resourced meaning overworked staff and lack of genuine service user involvement**

"The salami-slicing of budgets and means-testing means people get moved from service to service because it's cheaper - there's no personal choice in that."

"If Healthwatch want to do a visit they should go to [wards] at the [hospital] in the early hours of the morning; chaos due to lack of adequate staffing."

"The warden for the sheltered housing where I live is totally absent because she is overseeing 5 wards. They are completely overworked with no support."

"There need to be people who are affected by services designing, monitoring and holding those services to account."

#### **4. Communication of information occurs in way that ignores personal dignity**

“My experience with information services is that there has been too much signposting. There’s no point passing us on because we will forget! It is a very mysterious process getting support.”

“Organisations want to pass you on a lot of the time, or they only give us partial information.”

“Respect is needed. Social services should not approach people with dementia alone as unfamiliar.”

“My Carers Check was an online Survey Monkey type automated system - no personal contact.”

“We were told to go to so many different places at the hospital which was so confusing because the instructions were more often than not inaccurate. If user and carer not given appropriate information how can we be in control? We need full information about things like blood tests and implications.”

“In hospitals the staff all foreign now with very strong accents and poor English - I couldn’t understand what was being said and therefore what choices I was making.”

#### **5. Need for more coordinated and respectful system**

“I felt such pressure to pay privately and to have my wife at home. I’m 85 and I feel I cannot cope. I was given 3 appointments without any co-ordination.”

“Care has been turned into transactions and turning commissioning into contracts - where is the person needing health and social care within this systems culture? They are lost.”

#### **6. Dementia diminishes assertive capacity to make choices and have needs understood. Advocacy is essential or else dementia will almost certainly lead to undignified care.**

“We had a bone density scan at the [hospital]. It was a very good service but staff are clueless about dementia. It should be flagged up on the patient’s notes so the carer can help as needed but that information just doesn’t get passed on.”

“Carers generally need more support in hospitals, like an advocate to help them through the system and to speak out when necessary on their behalf - especially for carers who are older and are tired and exhausted themselves.”

#### **7. Waiting times and wasted appointments are a massive frustration**

“Timing of appointments for carers needs to be accounted for too. How can I care for [my wife] when I have to have an appointment early in the morning?”

“We had a situation last summer where my daughter had an appointment at the [hospital] at 1.30pm but we didn’t get home until late that night. They knew I was a carer so I was frantically trying to call people who could go and look after [my husband]. No consideration or individual care.”

## Focus Group 3

### Dignity in Care- Focus group report.

Every year Headway Oxfordshire helps to improve the lives of over 400 individuals affected by brain injury. Headway Oxfordshire offers a high quality rehabilitation, advice and support to individuals with an acquired brain injury. Through our centre, service users have access to a range of activities that complement their formal rehabilitation. We encourage socialisation and peer support with the aim of reducing anxiety and increasing confidence. Our Community Support Team work with individuals in hospitals, their home environment and out in the community. Our Personnel assistants work 1:1 out in the community to increase independence and every day skills.

A group of 12 service users met at Headway Oxfordshire on 17.3.15. The facilitator explained the aims of the Dignity in Care project and we used the framework for whole group discussion, then we split into smaller groups to discuss some of the questions in more detail.

Service users had used a range of services, including hospital wards, OTs, physiotherapists, private care agencies, nursing homes and voluntary groups.

The most important dignity 'do' identified was to listen and support people to express their needs and wishes. Several service users reported that even when they have expressed a preference a carer will sometimes try to persuade them to do something else e.g. not go out when it is raining. This concept of not being treated like an adult, or of being treated as if they were stupid, was a recurring theme in the discussion and a cause of great annoyance.

Most service users said they were consulted about aspects of their care and given some choice about it, but one service user reported an experience of care being set up for him while he was in hospital without him being consulted. Nobody recalled being given any assistance to express their likes or dislikes. None of them knew about advocacy services. Several service users were satisfied with their level of choice about their services, but said their choices were often limited by a lack of knowledge about available services. One service user reported that often carers did not really know him and what he is capable of, so they would judge him and what he can do without having enough information and understanding about his condition.



Communication was an issue for many, with one service user reporting that often carers didn't fully realise what their communication difficulties were.

Some service users had very positive experiences of care that made them feel good about themselves. This was when their carer respected them as a person, really understood them and their condition well and was able to support them to make decisions. Negative care experiences were mostly about not being listened to or choices not being respected. Being treated as if they were stupid was a common theme too. One service user reported that a carer had made demeaning racist comments towards him, but when he reported it to a manager that staff member was removed. Service users also said that they did not like being told what to do by their carers, for example one service user was asked to change TV channels as the carer did not like the religious TV show he was watching. One service user also had a bad experience of a carer exploiting her but when she reported this to the manager she was taken seriously and the carer was investigated and dismissed. Other things that service users did not like carers to do was to be impatient with them, not use their names and abuse handicapped facilities.

The main recommendations from the group for Healthwatch Oxfordshire to take forward were:

1. In order to respect a person and treat them with dignity, carers need to be fully informed about individual's conditions, what they can and can't do and how they would like to be supported. This information should be easily accessible to new carers. Care staff should be better educated about the condition of the person they care for.
2. Service users are often unable to make choices and have control over their care (one of the Dignity Do's) due to a lack of information about the range of support available. This sometimes results in people not receiving adequate support for extended periods, particularly when coming out of hospital.
3. Carers need to treat service users as a person by listening carefully to their needs and wishes. Carers must get to know the service user and their condition well so that they can assist the service user to express their wishes fully.

Report written by Claire Twinn. Service manager of Headway Oxfordshire.  
24.4.15

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## Appendix 2: Dignity in Care Award Winners 2015

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The Dignity in Care Awards 2015 are an initiative run by Age UK Oxfordshire in partnership with Healthwatch Oxfordshire, to celebrate local people, places and initiatives which are giving outstanding care and have gone that extra mile to deliver real dignity in care.

### Award for an unpaid carer

**Winner: Ruth Najeme**

Ruth is a trained nurse and cares for her mother at home. Ruth's mother is in her 90s and suffers from a number of serious health conditions. She is totally bedbound and is unable to speak. Ruth has been put forward for this award by a local GP.

*"Whilst Ruth is a trained nurse herself, the devotion and care which she has given to her mother is absolutely exceptional... Ruth has used her nursing skills and love to save her mother's life and care for her at home in a way that is quite remarkable. As a GP, with 30 years' experience, I have never seen the likes of this skill and devotion from a carer or relative."* Dr H

### Award for Care or Support Staff (4 Awards)

**Winner: Claire Fuller**

Claire has worked as a Home Support Worker for Greigcare in Banbury for 6 years. Claire has been put forward for this award by a family member of someone she cares for.

*"In my opinion, Claire is unbelievable. My wife has vascular dementia and is confined to a wheelchair. For the past two years Claire has treated my wife at all times with dignity, compassion and tenderness. She frequently goes the 'extra mile' to ensure my wife is comfortable and content. My wife trusts Claire implicitly and is 100% at ease with her... During the time that Claire is with my wife, she feeds her lunch, washes her hair, does her nails and has conversations with my wife (who speaks very little), but whom I am sure understands Claire at all times."*

*Claire is always immaculately dressed and has a smile on her face at all times. In my opinion, I believe she just loves her job as a carer.” Mr B*

### **Winner: Vicky Bauckham**

**Vicky has been a Care Worker at St Andrews Care Home in Headington for 18 years. Vicky has been put forward for this award by a family member of someone she cares for and her Manager.**

*“I love that Vicky always greets me when I enter the care home. She has a great sense of humour and often makes me laugh. She instinctively knows if I am worried about mum and she will sometimes send me a photograph of mum later or maybe the following morning, illustrating that mum is smiling and happy.” Mrs R*

*“Vicky is very devoted to her residents - she treats them like family, which is comforting for their family members. She really goes that ‘extra mile’ and she has a good way with people to help them achieve their potential within the home. She gives one to one special attention and helps residents to get involved in activities by putting a lot of thought into what their capabilities and interests are.” Manager*

### **Winner: Olwen Davies**

**Olwen has been the Support Coordinator at Oxford Options Health and Wellbeing Centre for 5 years. Previously Shotover Day Centre and Rectory Road, she has been working with the service all together for 26 years. Olwen has been put forward for this award by the family member of a service user.**

*“Leaving one’s husband at a day centre for the first time is so hard. Olwen with her understanding and warmth helped ease this step for me more than I can say. She gave me the confidence in knowing that my husband would be well cared for, and his individuality respected. This, in turn, gave me ‘permission’ to take this much needed break.*

*I had great confidence in the way that Olwen worked with my husband...Olwen helped him to feel valued and respected and he was relaxed and happy there... There is no doubt that she enabled me to carry on caring for my husband at home for as long as I did.” Mrs H*

### Winner: Emma Riley

Emma is family carer as well as a qualified social worker. She has worked as a Community Support Worker for Headway Oxfordshire for 3 years, supporting people affected by acquired brain injury. Emma has been put forward for this award by a number of people, including service users, their family members, and her Manager.

*“I always know that I can contact Emma if I need advice or reassurance... Without her reliable, friendly support and yet also real professionalism, I am not sure I could have made it through the year. In a world which, for me as a brain injured person, often feels frantic, confusing and overwhelming, knowing someone who genuinely cares and tries not to judge is a lifeline back to society.” Ms B*

*“Emma has shown us unfailing courtesy throughout. She is never condescending and treats us both with the utmost respect, but she is also fun and brings much needed laughter into our lives.” Mrs L*

### Award for leadership in dignity in care Sponsored by Oxfordshire Association of Care Providers

#### Winner: Christina Walford

Christina is the Manager and Founder of Autumn Years Care in Thame. Christina has been put forward for this award by her colleague and the family member of a service user.

*“Christina has shown time and time again that dignity and respect to her means everything. Not just for the clients but also towards her staff. She treats each client as a human being... she visits every client personally; to make sure they are happy. As she always says “I wouldn’t expect my carers to do anything I wouldn’t do”. She leads by example.” Colleague*

*“Christina had no hesitation in going beyond of the call of duty for me and my mother - helping me out of hours and answering phone calls. She and her girls were absolutely outstanding. My mother passed away this year. The last 7 months of her life were made so much more tolerable by wonderful the care from Christina.” Mrs L*

## Award for a care or support setting or service

**Winner: Wallingford Health and Wellbeing Centre**

The team at Wallingford Health and Wellbeing Centre include: Kerry Coleman (Manager), Isabella Godin, Ruth Evans, Sue Newman, Katie Evans, Anita Gray and Laura Fisher and Carol Harrison. They have been put forward for this award by a Carers Oxfordshire Outreach Worker and the family member of a service user.

*“All the staff are, without exception, kind and caring of the clients whatever their needs, disabilities or frailties. Whenever I have visited to run a carers group, the staff can be seen sitting with clients, bathing them or doing a meaningful activity...each client is treated as an individual. They advocate for those clients who need it too, making sure other agencies treat them with the respect they deserve.”* Outreach Worker

*“When I take my husband round in the wheelchair, sometimes I am so exhausted and when I walk through the door they just know and someone will always come up to me, see how I am, give me a hug, chat with me or offer me a drink. They are all a team, caring personified.”* Mrs E

## Award for innovation in Dignity in Care Sponsored by the Picker Institute

**Winner: Angela Nagle**

Angela is a Staff Nurse on the Dialysis Main Unit at Churchill Hospital. Angela has been awarded for her work in promoting the concept of ‘Shared Care in Dialysis’ at Churchill Hospital.

Angela has led the team of nurses in enabling any patient, or relative who wants to be more involved in care, to be able. The involvement ranges from completing paperwork, and a self-assessment of how they are feeling, taking and recording their weight, measuring their blood pressure. Many then progress to lining and priming and programming their dialysis machine to inserting needles and being completely independent in their dialysis.

Angela has assisted in developing a range of concepts to support ‘Shared Care’- badges for staff to wear saying ‘Ask me about Shared Care’- pens for patients and visual step by step guides for setting up machines.

*“Angela is persuasive and creative in how she engages patients and supportive of their anxieties and concerns. She has also shown that many patients are keen to be active in some parts of their care.*

*I can see that this change in care delivery has had a valuable impact on the peer relationships of patients and the support they offer each other.*

*Fundamentally, Angela’s work has reshaped the whole ethos of what a dialysis unit means for me and that rather than a place of ‘illness’ it is a place where we can promote ‘health’ by patient involvement.”* Matron

## **Josie’s Award (2 Awards)**

### **Winner: Pat Ross**

Pat is from Oxford and has facilitated the Oxford Mind Carers Group for many years, in a voluntary capacity. She has lived experience which she draws on to work with carers who are supporting loved ones who have mental illness. To enhance this work she became a governor of the Oxford Health Foundation Trust, Chairs the Response Housing Carers Group and is a retired nurse.

*“Pat has been most supportive to me. She understands how carers such as myself are affected by the very stressful role of being a carer of loved ones who have mental illness.*

*I manage depression, anxiety and panic attacks brought on by my situation in order to prevent a relapse. Pat’s support is integral in helping me to keep well and able to continue to care for my sons.*

*She is most accessible in providing support. She is warm and welcoming to all. She listens carefully to what the carer is saying and she will focus on what the carer needs. Carers can often feel lost and don’t know where to go. Pat will give good advice and she is available to talk to at the end of the phone, by email and face to face.*

*Pat’s work provides carers of those with mental illness the dignity to carry on caring and the support to develop the skills to continue to help their loved ones to recovery.”* Mrs C

### **Winner: Christine Tucker**

Christine is from Goring and is a founding member of the Goring Carers Group, she was also the primary carer for her husband for many years.

Christine freely shares the benefit of her considerable experience with other carers. She is keen to promote the welfare of carers in her community and to guide them towards services that are available.

Christine has sought opportunities to plead for a better deal for carers, for example with the local MP, and also represents carers interests as a member of her local medical practice Patient Participation Group.

*“Chris is widely respected and admired in her local community for the selfless care she gave to her ailing husband. She offers valuable support to other carers and is an effective spokesperson on their behalf.*

*Chris is know for her warmth, openness and good humour...Carers speak of the way that she always has time to listen, to encourage and to offer practical advice. Chris is outstanding among carers. She showed exceptional dedication in looking after her husband, while still finding the time and energy to support individuals and to seek ways of improving the welfare of carers.” Mrs A and Mrs H*

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# Appendix 3 - Detailed responses from commissioners and providers

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## Oxfordshire County Council response

### Improving Communication

*1. Communication be improved between staff and patients and their families, understanding that this communication must be two-way. Respondents to this survey report feeling they are being 'done to' and are not actively involved in their care.*

Oxfordshire County Council is committed to making sure that communication is open and two-way. We have recently revised our Adult Social Care Policy Framework and accompanying operational guidance to ensure it is all compliant with the Care Act 2014. The guidance has been written to be equally accessible to people who use services, their families and staff. This means processes and decision-making are open to all concerned, making balanced discussion and genuine joint planning of support possible.

We have developed and improved what is available to people in the way of information and advice, both online and in booklet form. Again, this makes informed discussion and planning easier. We commission the Community Information Network which trains and supports volunteers to help people find out what is available in their own communities, making sure they have the opportunity to be active in their own wellbeing, independence and support when needed.

The council's Engagement Team works with people with disabilities, mental health problems and learning disabilities, as well as older people, to make sure we understand what matters most to them, and to make improvements where they are most needed. The team is also working with commissioners to develop a model of co-production that will see service users directly involved in the design and commissioning of future services. This model is already being employed in the redesign of respite care and the council is in the process of developing training for commissioners that is service user led.

*2. Access to support services which facilitate dignified care be more widely promoted and offered. Specifically, we heard about difficulties in accessing advocates and interpreters, but this also applies to the inclusion of carers.*

The council is committed to commissioning support services that provide better access to good quality care and support as early as possible. There is



a general expectation that all care and support services commissioned by the council are delivered with dignity and respect and providers are expected to adhere to the 'Dignity Do's', namely:

- Have a zero tolerance of all forms of abuse
- Support people with the same respect you would want for yourself or a member of your family
- Treat each person as an individual by offering a personalised service
- Enable people to maintain the maximum possible level of independence, choice and control
- Listen and support people to express their needs and wants
- Respect people's right to privacy
- Ensure people feel able to complain without fear of retribution
- Engage with family members and carers as care partners
- Assist people to maintain confidence and positive self-esteem
- Act to alleviate people's loneliness and isolation

Our new Information and Advice Strategy articulates the council's drive to ensure access to advice and support that enables people to fully understand the range of options available to them to meet their care and support needs.

The planned development of an e-marketplace will offer individuals, carers and professionals the opportunity to choose and purchase good quality care and support services from providers specifically selected by the council.

The council also runs campaigns that promote access to support services and equipment which facilitate dignity in care. For example, our current assistive technology campaign promotes the availability of devices that can be used in a person's home to improve their quality of life and that of their carer, and help them maintain independence. Access to this kind of support is promoted through face-to-face events, press releases, newsletters, media campaigns and information on the county council website.

Furthermore, the council commissioned Community Information Network operates across the county through information drop-ins, over the phone or visiting people at home, enabling individuals to access local support services, activities, financial advice and social care.

Recently the council has commissioned an expanded advocacy service in response to the requirements of the Care Act 2014. The service has reached an additional 53 people to support them in accessing or reviewing their support and care compared to the same period last year. In the first six months (from April to Sept 2015), 70% of people using the service were seen within the target time of two days (hospital referrals) and five days

(referrals at home). In the last three months everyone using the service was seen within the target time.

A new contract for interpretation services has been established by a consortium, led by the Oxfordshire Clinical Commissioning Group and including health providers and the County Council. This will allow staff to access interpretation either face-to-face or over the telephone through a quick and easy online system. The new service started on 1 September and we will be monitoring it closely to make sure access across the health and care system is improved.

To support the inclusion of carers, the council has run workshops on addressing the initial problems raised about the new self-assessment process, which is designed to make it easier for more carers to get the information, advice and support they need. Following up from a meeting with Healthwatch Oxfordshire, in January 2016 commissioners are meeting carers about the self-assessment forms, to work together on practical improvements.

*3. Discussions about maintaining dignity be included in staff training and induction, and that this training should include: dementia awareness, limiting jargon and using plain English, two-way communication and a broader understanding of dignity.*

Staff training already includes dementia awareness and a broad understanding of dignity. The council is committed to the use of plain English and ensuring people are listened to and their needs and preferences are understood. The council hosts the Dignity and Dementia Champion Network, which examines the importance of dignity in the development of care models, and contributes to training. Many of the people who work in commissioning (and more broadly across the council) have signed up individually to be Dignity Champions.

## **Developing a workplace culture that supports Dignity in Care**

*4. Providers and commissioners work to ensure staff have the time to care, by increasing the proportion of time they spend with patients. This could be done through continued work to improve processes and paperwork, work to decrease staff sickness or through increasing allotted time for specific tasks. Recently, the National Institute for Health and Care Excellence (NICE) offered its first guidance for the social care sector that touches on dignity and the time to care, by recommending a standard for domiciliary visits of 30 minutes.*

The County Council remains committed to making sure that all visits for support at home are the right length for the person and the support they need, and in all cases are sufficient for care and support to be given with

dignity and respect. All visits involving intimate personal care such as help with washing or using the toilet will be more than 15 minutes long.

Our Workforce Strategy includes the promotion of Value Based Recruitment with organisations providing support and care at home. This supports providers to recruit people for their desire to work caring for others, and their commitment to values such as dignity and respect. A pilot for this type of recruitment was run with six organisations between November 2014 and June 2015. Results are being analysed and the method refined, so that this approach can be adopted as part of the council's new home care model, Help to Live at Home.

*5. Commissioners and providers in Oxfordshire broaden the discussion on dignity so that it encompasses all elements of dignified care (the do's can provide a guide) and that this discussion inform training, the development of care models or pathways. There is a need to help staff focus on the balance between patient choice and dignity, particularly when patients have a diminished capacity to make choices.*

The central principles of the 'Do's' from Dignity in Care 2015, as repeated in this report, are at the heart to the council's approach to support and care. Our Adult Social Care Policy Framework, with the associated guidance for staff and for the public, outlines our commitment to putting people at the centre of their own care and support.

Our priority is to make sure people are treated as individuals, have choice, independence and control, and that families, friends and carers of those who have support and care services are seen as partners, while helping people to stay safe from harm.

Commissioners at Oxfordshire County Council approach dignity in its broadest sense, and work with providers of adult social care to do the same. Our Home Care Standards were written jointly by people who receive care in their home and home care support agencies.

#### **Home care staff will:**

- introduce themselves when they arrive;
- know you and your support plan;
- be trained to deliver the support you need;
- always deliver support to a good standard.

#### **When your home care worker visits you, they will:**

- focus their attention on you;
- be pleasant and treat you with dignity and respect;

- do their very best to arrive on time and let you know by telephone if they are going to be late;
- tell you when they are leaving;
- check to see how they can best support you at the start of each visit;
- not rush you - they will help you at a pace that suits you;
- carry out all agreed tasks;
- make sure that you are comfortable at all times;
- communicate and discuss topics that interest you;
- check that you are happy with the support you are given and encourage you to tell us how they can improve;
- show you your care record if you ask for it;
- be aware that their visit may affect other household members.

*6. Providers do further work to develop an open culture that learns from complaints and isn't defensive so that patients and carers feel able to make complaints/report abuse without fear of repercussions. Respondents' reports of reactionary or defensive responses to initial concerns or signs of staff being managed harshly were some of the elements which caused concerns.*

The council's Comments and Complaints service is working even more closely with providers of adult social care to develop a culture of learning from complaints and concerns. This summer the team ran a workshop for residential care home staff to explore the need to share learning from complaints, and view these as a positive tool to promote improvement in services. Twice each year the council asks providers of support and care at home to share the complaints and compliments they received, what they learned from them and what has changed as a result. This is in addition to contract monitoring where complaint numbers are collected routinely.

There is a short film on the council's website in which John Jackson (Director of Adult Social Services) and Councillor Heathcoat (Cabinet Member for Adult Social Care) explain why they value hearing when something has gone wrong, and reassuring the public that they will not tolerate repercussions against anyone who raises a concern.

## Oxford University Hospitals NHS Foundation Trust Response

<p><b>Healthwatch Dignity Report recommendations</b></p>	<p><b>OUHFT response: Initiatives in place to ensure that dignity and respect are at the heart of individual’s care and treatment.</b></p> <p><b>Bullet points in bold indicate planned activity. All other items indicate existing and ongoing activities.</b></p>
<p>1. Communication be improved between staff and patients and their families, understanding that this communication must be two-way.</p>	<ul style="list-style-type: none"> <li>• A hospital passport is in place for people with learning disabilities to which are designed to give hospital staff helpful information that isn't only about illness and health.</li> <li>• A Trust wide compassionate care training programme has been introduced using the Trust Values.</li> <li>• The Trust has co-produced with voluntary and partner organisations a new Privacy and Dignity Policy.</li> <li>• The development and implementation of the ‘Knowing Me’ care planning document.</li> </ul>
<p>2. Access to support services which facilitate dignified care be more widely promoted and offered.</p>	<ul style="list-style-type: none"> <li>• <b>OUHFT will review advocacy arrangements at the Trust with a view to ensuring that access to advocates and other support is improved. For example, information will be put in patient packs and to promote Oxfordshire Advocacy services more widely.</b></li> <li>• Learning Disability Liaison nurse is available for supporting LD patients</li> <li>• Tracking and flagging in place so LD patients can be identified when in hospital</li> <li>• Interpretation and translation- there is new, improved provider, increased profile on the internet, a banner promoting the service is planned for the JR Welcome Centre and newly developed cards for patients to request services.</li> <li>• Carers’ Surgery - Carers Oxfordshire are working in the JR for 21 hours a week in hospital wards offering support, advice and</li> </ul>

	<p>signposting for carers. This is just started and will be piloted and evaluated.</p> <ul style="list-style-type: none"> <li>• Independent Mental Capacity Advocates (IMCA) - a piece of work is currently being undertaken to raise profile of IMCA services with consent to treatment and moving residents.</li> </ul>
<p>3. Discussions about maintaining dignity be included in staff training and induction, and that this training should include: dementia awareness, limiting jargon and using plain English, two-way communication and a broader understanding of dignity.</p>	<ul style="list-style-type: none"> <li>• The first session of the Trust induction day is about Trust values - how to talk to people and be respectful.</li> <li>• Induction day afternoon session is on dignity and dementia.</li> <li>• Session in induction on using plain English, multi-cultural understanding - language plain English</li> <li>• Safeguarding is a key theme of the induction</li> <li>• <b>We will review the inclusion of the induction day and other training on dignity and respect.</b></li> </ul>
<p>4. Providers and commissioners work to ensure staff have the time to care, by increasing the proportion of time they spend with patients. This could be done through continued work to improve processes and paperwork, work to decrease staff sickness or through increasing allotted time for specific tasks.</p>	<ul style="list-style-type: none"> <li>• The Trust has piloted a new scheme (Manchester Clocks) on two wards for measuring direct and indirect contact care time. This will be rolled out throughout the Trust and will allow OUHFT to understand better the levels of direct contact care time and to measure it over time with a view to increasing it where needed.</li> <li>• The Manchester Tool will help to inform the Establishment settings which are set twice per year and determine staffing levels and help set the roster. Currently acuity (patient needs) and professional judgement is used to set the Establishment settings - the Manchester Clocks Tool will add further intelligence to this.</li> <li>• There is an extensive ongoing programme of work to ensure safe staffing levels including assessment of direct contact care, twice daily review wards on all four sites which record and review shifts and move staff around if necessary.</li> </ul>
<p>5. Commissioners and providers in Oxfordshire broaden the discussion on dignity in work places, so that it encompasses all elements of dignified care</p>	<ul style="list-style-type: none"> <li>• The Trust Values encompass the principles of privacy and dignity and are raised at 1:1s and appraisals.</li> </ul>

<p>(the do's can provide a guide) and that this discussion inform training and the development of care models or pathways.</p>	<ul style="list-style-type: none"> <li>• The Trust has a range of policies to support privacy and dignity : <ul style="list-style-type: none"> <li>○ Privacy and Dignity Policy (includes reference to the Dignity 'Do's')</li> <li>○ Chaperone and Intimate Examination Care Guidance Policy</li> <li>○ Transgender Guidance</li> <li>○ Safeguarding Policies (Adults and Children)</li> <li>○ Dementia Strategy</li> <li>○ Delivering Same Sex Accommodation Policy</li> <li>○ Learning Disability Policy</li> <li>○ Consent to Examination or Treatment Policy</li> <li>○ Raising concerns (Whistleblowing) Policy</li> <li>○ Management of Patient's Comments, Concerns and Complaints Policy and Procedure</li> </ul> </li> </ul>
<p>6. Staff be helped to focus on the balance between patient choice and dignity, particularly when patients have a diminished capacity to make choices.</p>	<ul style="list-style-type: none"> <li>• There is dementia training on induction day (as outlined in 3).</li> <li>• Dementia training in departments is led by Dementia leads.</li> <li>• Seven Dementia friendly computers to support reminiscence in hospital.</li> <li>• The Dementia information café is held monthly and attended by staff, voluntary organisations and carers.</li> <li>• There are a range of policies which support staff in understanding balance between patient choice and dignity particularly when patients have a diminished capacity to make choices - e.g. Learning Disability Policy,</li> </ul>
<p>7. Providers do further work to develop an open culture that learns from complaints and isn't defensive so that patients and carers feel able to make complaints/report abuse without fear of repercussions.</p>	<ul style="list-style-type: none"> <li>• Posters and leaflets throughout all sites about how to complain.</li> <li>• Mediation training has taken place focusing on effective resolution meetings. 25 staff including consultants, Divisional Nurses etc have been trained. Extremely well received and <b>further training is planned next month.</b></li> <li>• Complaints training - 3 x 2 day courses for around 40 staff has taken place. <b>Further</b></li> </ul>

	<p><b>training is being commissioned.</b> Well received and undertaken by a range of staff.</p> <ul style="list-style-type: none"> <li>• A new PALS escalation system has recently been implemented for Inpatients in order to resolve issues speedily - PALS staff contact Sister within half an hour who has half hour to deal with situation and let PALS know. If not, it is escalated to Matron and then Divisional Nurse within same time scales. Since implementation, there has not been a need to escalate to the Matron as all issues have been resolved by the Sister.</li> </ul>
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## Oxford Health Foundation Trust Response

OHFT responded to each of the recommendations below sharing the work we have started and plan to do.

**1. Communication to be improved between staff and patients and their families, understanding that this communication must be two-way. Respondents to this survey report feeling they are being ‘done to’ and are not actively involved in their care.**

We recognise the importance and necessity of working in partnership with patients and their families/ carers - if this is at an individual care level or as part of continually improving our services through working together in the planning, delivery and review of service changes/ developments. This commitment is in our strategic plan and is part of developing and reviewing our current patient experience strategy, to improve the consistency and build on how we engage and involve people. We will be consulting on our revised patient experience and involvement strategy from November 2015.

We routinely ask patients if they feel involved in their care, this is one of the trust wide core questions we introduced across all surveys, below are the results for the last 6 months.

Were you involved as much as you wanted to be in decisions about your care and treatment? (n=856)

	Apr-15	May-15	Jun-15	Jul-15	Aug-15	Sep-15	Grand Total
No	7%	9%	12%	6%	2%	4%	6%
Yes, definitely	63%	68%	44%	65%	75%	54%	65%
Yes, to some extent	30%	23%	44%	28%	23%	42%	29%



We support our staff to use frameworks and systems to involve patients and their families/ carers in their care, some of these are mentioned below. However this will require ongoing work and monitoring to improve.

- The Care Programme Approach (CPA) is used as a framework across the children, adult and older people mental health services as a way to assess needs and plan, communicate and review care with patients and their families/ carers. We have a quarterly audit process to review the implementation of the CPA process.
- We use routine clinical audits on all our inpatient wards to review patient's involvement in care planning and discharge.
- Patient, family and carer involvement in care planning has always been an important aspect of the CPA. The use of the recovery star has been introduced across all community adult mental health teams, with training for all staff, which supports the identification of joint goals and joint monitoring of progress.
- A series of care planning sessions have been held for staff working in adult mental health inpatient and community services in August and September 2015 with an emphasis on patient and family/ carer involvement.
- The trust has been implementing a new electronic care notes system and the care plan template in the system has a section to record whether a patient was involved in its creation, with an additional comments box for any specific information of note.
- The trust recently developed a care plan with Sue Ryder which has been introduced to ensure individualised and patient centred planning when someone is in their last days or hours of life. A key focus of the template is patient, family and carer involvement.
- The older people directorate are working on two key initiatives around embedding personalised care; one project is working with Thames Valley Strategic Clinical Network looking at application in primary care and then also applying personalised care planning within the Integrated Locality Teams; the second project on improving personalisation of care which is being supported by the Kings Fund and is being implemented within one of the District Nurse teams to support patients to identify their goals, what helps and hinders them with their health problems to inform the development of their care.
- Carers are supporting the trust to achieve the 'Triangle of Care' external accreditation ran by the Carers Trust, this scheme puts partnership working between patients, families/ carers and staff as a foundation. So far over 35 mental health teams and wards have completed a self-assessment against the 'triangle of care' standards

and the results have been shared and discussed by the forums members including carers. The self-assessment work to date has highlighted some important themes for improvement and the Carers Strategy Forum has prioritised two significant areas to take forward; developing carer awareness training for staff and a trust wide review of information available for carers both provided by teams and on the trusts website. An action plan is in place to address these areas of improvement.

**2. Access to support services which facilitate dignified care be more widely promoted and offered. Specifically, we heard about difficulties in accessing advocates and interpreters, but this also applies to the inclusion of carers.**

We have an internal PALS which provides advice and information as well as support to access advocacy and interpreting services. The PALS Team is very active and regularly goes out to services and hold stands at local community events. The team routinely runs over 35 PALS surgeries across the trust, held at least monthly.

The trust was part of a recent whole system re-tender for telephone and face to face language interpreting and the new provider started from 1st September 2015. Our Equality and Diversity Lead was involved in the re-tender and is responsible in the trust for monitoring the contract, levels of use and supporting teams with access.

All our patients and their families/ carers are able to contact free independent advocacy services (SEAP), access to this service is promoted by a poster, information leaflet and regular surgeries in all inpatient wards, on the trust website and in key patient information leaflets for example 'how to make a complaint'.

We are pleased to be working with Age UK on introducing circles of support to help older people to stay as independent as possible and ensure they have the information they need. We also work with Age UK on supporting initiatives such as volunteers working as care navigators at some of our community hospitals and dementia advisors working alongside our staff in memory clinics.

**3. Discussions about maintaining dignity to be included in staff training and induction, and that this training should include: dementia awareness, limiting jargon and using plain English, two-way communication and a broader understanding of dignity.**

Maintaining patient's dignity is reflected in our values - caring, safe and excellent.

The trust wide corporate induction includes presentations by patients and carers about their experiences and what is important to them, the PALs team and the Equality and Diversity Lead, which include discussions about dignity, respect and the importance of involving people in their care. There is also a specific five day programme followed by a work based competency assessment for healthcare assistants as part of the national healthcare certificate which covers dignity and communication.

The trust offers a two hour basic dementia awareness training open to all staff including non-clinical staff. As well as a 6 month training course for healthcare assistants working with people with dementia which is more in-depth, VRQ level 2 award in awareness of dementia/ level 2 certificate in dementia care.

We have also relaunched our own annual staff awards recently with prizes presented at the AGM in September 2015; one of the awards was around dignity and respect. We had patients, parents and carers nominating staff and teams as well as judging nominations for the staff awards.

As mentioned above we are developing carer awareness training for staff with carers, which will cover topics which as confidentiality, communication, information sharing, capacity and consent.

To ensure we consider the 10 Dignity Do standards more fully we will be making a recommendation to our next Learning and Advisory Group in December 2015 that the standards are taken into account when we design and review training courses going forward. As well as reviewing our current trust wide core questions used across all patient surveys to include a specific question around dignity in care so that we can monitor and target improvements.

**4. Providers and commissioners work to ensure staff have the time to care, by increasing the proportion of time they spend with patients. This could be done through continued work to improve processes and paperwork, work to decrease staff sickness or through increasing allotted time for specific tasks.**

As part of the national safer staffing work all our wards now complete at least a 6 monthly review of the amount of direct care time spent with patients split by registered and unregistered staff. The results are presented to the board of directors and published. Each ward team is asked to review the detail of their results to identify and make improvements i.e. reducing how many interruptions staff to staff, where equipment is placed on a ward to reduce movement time, how staff and skill mixes are used, and how to reduce the completion of paperwork away from the patient.

Our reablement service work with patients to help them to recover and become as independent as possible. Patients are normally seen by the service for up to 6 weeks based on their needs, in this time the length of visit times will decrease as patients become more and more independent. We are currently working in partnership with Oxford University Hospitals to develop an alliance to deliver an ambulatory model of care for frail older people. The two Trusts will provide a single managed pathway of care bringing together services to provide the best possible outcomes and experiences for patients; this will include bringing together bed based care, Emergency Multi-Disciplinary Assessment Units (EMUs), Hospital at Home, Reablement and Supported Hospital Discharge Services.

**5. Commissioners and providers in Oxfordshire broaden the discussion on dignity so that it encompasses all elements of dignified care (the do's can provide a guide) and that this discussion inform training, the development of care models or pathways. There is a need to help staff focus on the balance between patient choice and dignity, particularly when patients have a diminished capacity to make choices.**

We would welcome and be interested in working with partner organisations to identify opportunities of joint working in relation to raising the profile around dignity in care.

As mentioned above we will be making a recommendation to the Learning and Advisory Group in December 2015 that the 10 Dignity Do standards are taken into account when we design and review training courses going forward.

All our staff receive mandatory safeguard and mental capacity training which provide staff time to discuss how they ensure patients are treated with dignity at all times.

**6. Providers do further work to develop an open culture that learns from complaints and isn't defensive so that patients and carers feel able to make complaints/report abuse without fear of repercussions. Respondents' reports of reactionary or defensive responses to initial concerns or signs of staff being managed harshly were some of the elements which caused concerns.**

We are surprised to hear this feedback as we work hard to make it easy for people to raise a concern or make a complaint, to learn from concerns raised, and to ensure concerns raised do not affect a patient's current or future care.

As mentioned above we have a PALs which is there to help provide advice or information, support to sort out a local concern quickly, the opportunity to

comment or make a suggestion to improve our services and help with raising a formal complaint. The PALS team run over 35

PALS surgeries across the trust, each held at least monthly. PALS surgeries are a valuable way of seeking feedback about people's experiences, both positive and negative, and also about working with ward staff in resolving issues of concern at a local level, in a timely and positive manner. Over the last 6 months we have seen an increase in the number of concerns raised and a decrease in the number of formal complaints which could be a possible indication that people are satisfied with how we respond to informal concerns.

We have systems in place to support a learning culture around complaints, these include:

- A weekly review of complaints alongside incidents and other quality measures. This also includes looking at the outcome of complaints.
- A quarterly system to report on actions following complaints and progress against timescales
- A telephone survey is offered to every complainant after the investigation has completed to find out the persons experiences so that the complaints service can continue to improve in response to users experiences.
- 6 monthly complaint panels are held with each clinical directorate which include attendance from 1 Executive Director and 1 Non-Executive Director to review a random selection of complaint cases to ensure the procedure is appropriately followed, the investigation is robust, our response is open and honest and to ensure appropriate actions are identified and actioned.

As you will see we are committed to ensuring patients and their families/ carers are treated with dignity and respect. Thank you again for the opportunity to see the draft report prior to publication.

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## Appendix 4 & 5: Data tables, questionnaires and guides

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Due to their length, the questionnaires used in this study and the data tables are available in separate appendices. Appendix 2 & 3 will be available at [www.healthwatchoxfordshire.co.uk](http://www.healthwatchoxfordshire.co.uk) or you can contact the office on 01865 520520 or on [hello@healthwatchoxfordshire.co.uk](mailto:hello@healthwatchoxfordshire.co.uk) to request a copy.