Living and Ageing Well with Dignity: Telford & Wrekin





About Healthwatch Telford and Wrekin

Healthwatch Telford & Wrekin is an independent champion for local people who use health and social care services and we are supported by Healthwatch England in exercising our statutory powers to empower people to have their voice heard about the delivery of those services. We listen to what people like about services and what could be improved. We then share those views with those who have the power to make change happen. We also help people to find the information they need about services in Telford & Wrekin.

Our Mission

"To make health and social care services better for the people of Telford & Wrekin"

Our Aims

- 1. Enable people to easily access the right services through effective signposting, information and advice.
- 2. Influence and help shape the planning and delivery of health and social care through using intelligence and insights from people's experiences.
- 3. Be a local watchdog challenging local services and decisions to ensure the public voice has been heard and taken to account.

To be able to achieve our mission and our aims it is vitally important that people speak to us about the issues that matter most to them. Speaking to us about your experiences of any NHS or social care service will help make them better for you, your friends and your family.



Acknowledgements

We would like to say a huge thank you to all our volunteers who helped with Enter and View visits and reports, the dissemination of surveys and collation of information. Our volunteers support us with their time, their energy and their experience to help all areas of the community in ensuring health and social care services here in Telford and Wrekin are the best they can be for those that use them.

We would also like to say thank you to the services that contributed to the Enter and View visits, as well as those who completed the provider survey. The involvement of local health and social care services is essential for meaningful recommendations to be made and to enable us to recognise best practice. We would like to thank the following organisations who welcomed staff and volunteers on their visits.

Deansfield Residential Care Home

St George's Park

Princess Royal Hospital - Children's Unit, Wards 4 & 6 and A&E

Shropdoc (Shropshire Doctors Co-Operative)

Standford House

The Priory Nursing and Residential Home

Myford House Nursing & Residential Home

Lightmoor View

Hatton Court Care Home

Sambrook House Residential Home

Woodcote Hall

Malling Health



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Introduction

Treating people with respect and dignity in health and social care is a constant area of spotlight. People are often at their most vulnerable when they are using these services and so respect for dignity is hugely important. The number of initiatives promoting dignity in health care have been substantial. Whenever poor standards of care are exposed it is often regarded with shock and disbelief, however, we also see examples of care where despite the most difficult circumstances, people's dignity is highly respected.

When we are choosing care or support we want to know that dignity and compassion are valued and that human rights are considered as paramount. We have undertaken this research to particularly understand what improvements need to be made in the care and support of people with dementia.

Methods

 We conducted a survey asking people what dignity meant for them and sought examples of being treated with dignity in health and social care services.



- We conducted a series of Enter and Views in which we explored service provision from the perspective of dignity, particularly for those living with dementia. Volunteers and staff provided their own views alongside those of users.
- 3. We conducted a survey of local health and social care services to seek information about their provisions for those living with dementia, as well as their family and carers.



What is Dignity?

During the week of Dignity Action Day on 1 February 2018 we decided to ask people what dignity means to them. We also wanted to find out what examples they had of being treated with dignity in health and social care.

The Dignity in Care¹ website has this to say about Dignity Action Day:

"Dignity Action Day aims to ensure people who use care services are treated as individuals and are given choice, control and a sense of purpose in their daily lives."

If you have ever completed a survey in a health and social care setting you will know that a common question is:

"Have you been treated with dignity and respect?"

In the 2016 Adult Inpatient Survey, 246 patients at Princess Royal Hospital answered a resounding yes (9.18/10) when asked:

"Overall, did you feel you were treated with respect and dignity while you were in the hospital?"

Dignity in Care have produced 10 points that must be followed if one is to become a Dignity Champion². We were interested to see how many of these were perceived by people in Telford and Wrekin as being part of their understanding of dignity. These "dignity do's" are as follows:

- 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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¹ https://www.dignityincare.org.uk/

² https://www.dignityincare.org.uk/register/



- 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

In 2012, Shropshire Partners in Care asked local providers in the health and social care sector to complete a survey about the 10 point dignity challenge³. It demonstrated that the majority of services aimed to promote dignity amongst their staff and provide training in this area.

The aim of this survey was to explore the meaning of dignity among users of health and social care services and their carers, as well as a follow up to the 2012 survey. Insights and recommendations were sought as to practical and actionable ways of including dignity in the provision of health and social care.

Methodology

We collected surveys face-to-face during a visit to a care home (11), to the Princess Royal Hospital (3) and at Meeting Point House (3). A further two were completed online from a link provided by the Clinical Commissioning Group and a visit to our website.



³ http://www.spic.co.uk/downloads/cat_view/24-training-resources/47-dignity-information-and-handouts



A total of 18 surveys were returned. 14 respondents were female and 4 male with an age range of 25 to 80+. 4 identified as carers and 11 as having long term conditions.

Findings

What does dignity in health and social care mean to you?

The word **respect** was identified as an important element of dignity, not just in how they are treated but in how they treat others.

"Being respected as a person should be and showing respect back to those who care for us"

How people are treated was significant, with very clear descriptions of what **being treated with dignity** means. Many wanted **recognition of self**, whether through being addressed by their name and "not a generic dearie etc" or "being treated like a person and not just the next on a conveyer". Their **inclusion** was also important through being "informed of procedures" but also being **involved** in their own care.

"Being talked to, not at"

Dignity means being invited to have an **active role** within one's care, whether through being "listened to" or having one's "opinion valued".

"Being treated as a person with feelings; this means respecting my choices & preferences - offering me choices and being involved in my care/support"



There are also actions that others can take, in addition to recognising the individual as a person, which can help them to feel they are being treated with dignity. **Privacy** was important in this but people also identified aspects such as having needs that caregivers are trained in and the environment is suited to - **personalised care** supported their experiences of dignity.

"Being cared for according to my needs"

In summary, respondents constructed dignity as meaning:

- Being treated with respect.
- Being recognised as a person.
- Feeling included and involved in one's care.
- Being given an active role in one's care.
- Feeling that their privacy was maintained.
- Being given the personalised care that they needed.

I am/was treated with dignity in health and social care when...

Sadly, not all people felt that they had been treated with dignity. However, lots of examples were given of individual health and care professionals who had gone above and beyond to ensure that their patients felt that their dignity was respected.

One respondent spoke of how important the care he received was, that it helped him when he was struggling.

"Thank heaven for carers who really care. It's worth a lot. Thank you."

Others gave examples of staff respecting their need for privacy and making sure that patients were informed. Others identified those that were available when



needed to provide assistance, often at a time when they felt vulnerable. Just the simple act of being "covered" was used in 4 of the examples.

"My mom was treated with respect and dignity while in A&E...

Doctors/nurses explained what and why they were doing things,

covered body"

In summary, respondents gave numerous examples of when individual health and social care professionals had treated them with dignity. Important elements of being treated with dignity include:

- Being cared for by those who care.
- Feeling that their privacy was maintained.
- Being informed about their care.

What local people say about dignity in local services

We also decided to explore experiences of dignity within the feedback available on our website received between February 2016 and February 2017. During this period a total of 59 services were reviewed, including all areas of health and social care, with a total of 535 separate pieces of feedback.

The term 'dignity' was used 9 times. The reviews were mainly positive and included both hospital and ambulance services. Interestingly, it was not used for other types of services. Content mainly focused on how the patient was treated including being informed, having their privacy maintained, being understood, and being respected.

Thematically, we use Dignity and Respect within which are three sub-themes: confidentiality/privacy, equality and inclusion, involvement and engagement. These were identified within 16 reviews.

50% of the feedback came from hospitals and these ranged from 1 to 5 star ratings. Those that were identified as negative focused on a lack of support for privacy



whilst those that were positive recognised the staff, who kept them informed and treated people as individuals.

30% of the feedback came from GP surgeries, where the star ratings ranged from 1 to 5. Negative feedback focused on how they were treated, particularly identifying that they did not want to be quizzed about sensitive issues by reception and staff and wanted more personalised care. Positive feedback identified doctors who had taken their time and listened to the patient.

20% of feedback came from care homes. These had star ratings 4 to 5 and identified staff who had treated them as a person.

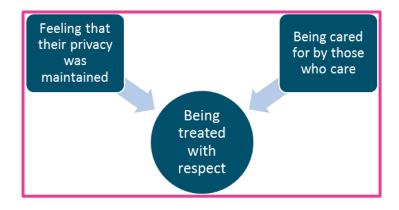
The feedback identified within our Feedback Centre supports the sub-themes identified within the survey.

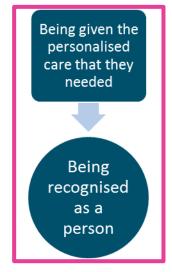


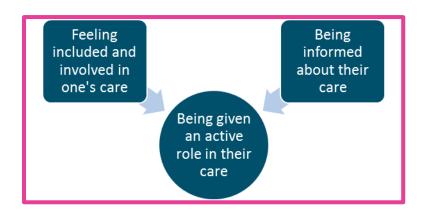


Themes we identified

Using the elements that we identified within the survey we grouped them as follows:







This left us with three overarching themes:

- Being treated with respect
- Being given an active role in their care
- Being recognised as a person



Enter and View Visits



A series of 16 Enter and Views, consisting of 19 visits total, have been conducted as part of a programme of work on Dignity and Respect in health and care settings. Some also focused on Walk-In/Out-of-Hours and emergency health care whilst others had a focus on Dementia.

What are Enter and View Visits?

Part of the local Healthwatch programme is to carry out Enter and View visits. Local Healthwatch representatives carry out these visits to health and social care services to find out from those who use the services how they are being run, and make recommendations where there are areas for improvement. The Health and Social Care Act allows local Healthwatch authorised 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. Enter and View visits can happen if people tell us there is a problem with a service but, equally, they can occur when services have a good



reputation - so we can learn about and share examples of what they do well from the perspective of people who experience the service first hand.

Findings

A total of 10 Care Homes, 4 Hospitals and 2 GP Out-of-Hours services were visited by our volunteers and staff between April 2016 and April 2017. The visits were informed by a list of dignity and respect topics to support the observational activities. During these visits we spoke to 166 patients and residents, 31 visitors and relatives, and 43 members of staff. The majority of visits were announced, with three unannounced.

Using the components of dignity that respondents shared within our survey we retrospectively identified examples of these within the Enter and View reports with a particular focus on actionable examples.

Being treated with respect

Being treated with respect

Care home staff were often considered easy to talk to, kind, considerate and "lovely". They were observed "taking time to talk to them [residents] individually" and brought their faces level to residents when talking to them. However, some were described as not having "the right manners and can be rude" as well as "rough and ready" when getting residents dressed in

the morning. This seemed to be individuals rather than descriptions of staff in general.

In hospital, patients felt that clinical staff were respectful when they listened to them. In a survey of A&E patients the majority felt that doctors and nursing staff treated them with dignity, all felt that reception staff acted in this way. Staff apologised and explained why they had not answered call bells immediately.

In the out of hours GP practices staff were reported to sometimes appear "put out being asked for an appointment", however the comments were mostly positive.

Staff were "polite" and treated patients with "courtesy and respect".



Examples we identified

The attitudes of staff are vital in being treated with respect, for example those who are courteous and listen to users of services.

Feeling that their privacy was maintained

There were a number of examples of residents' privacy being maintained by staff including blankets and dignity screens being used when they were being hoisted in public places. Unfortunately, some examples were given where they were not including toilet doors being left open and staff not knocking before entering.

Observations made by our representatives on wards were generally positive. Staff, including nursing staff, care assistants, therapists and doctors/consultants, closed doors, pulled curtains and shut blinds around the patient's bed when they were being treated or their care discussed. However, for some patients this did not offer enough privacy - "the doctor's voice could be overheard quite easily as he talked with other patients during his 'round' in the ward". Observations made in the emergency department included numerous examples where privacy was not maintained including clinical staff sharing results with patients where others could hear. However, they also included examples of privacy being maintained. For example temporary screens were used when patients were brought in by ambulance and there was a private area available for staff to discuss sensitive issues with patients.

Patients reported some concern about "being asked to give some personal information" when at reception. However, practices had forms that could be filled in as an alternative or private areas that were sound proof.

Examples we identified

The use of blankets and dignity screens was identified as a high quality provision of dignity in care. Simple actions such as ensuring that conversations are not overheard and that sensitive discussions occur in secure locations can be important for users of health and social care. In GP services, if information is needed, forms can be used instead of requesting information directly.



Being cared for by those who care

Care home staff were reported to give residents their time. Some were called "caring carers" and in many of the reports staff were described as lovely.

Hospital staff spoke to patients so that they felt cared for and it helped them to feel less lonely.

Patients felt "helped and informed" by staff who treated them in a "caring way". Staff were reassuring and calm in their interactions.

Examples we identified

Those who cared were identified as staff who supported users of health and social care, ensuring that they were both physically *and* mentally comfortable.

Being recognised as a person.

Enter and View representatives identified a number of care homes where residents' names were used. One visitor told how her parent was treated very well, as "a name, not a number". There were also opportunities for residents to reminisce about and talk about their early memories with staff and visitors. This

Being recognised as a person

Patients were observed being addressed by name.

Patients felt "listened to and not rushed".

Examples we identified

Users of health and social care, across the three types of services, recognised how important it was to be addressed by name and to feel that they were recognised by their care provider.

demonstrates an actionable way in which they could be recognised as a person.

Being given the personalised care that they needed

In care homes many of the residents reported being able to personalise their rooms. Staff understood the individual's needs and responded to them.



Clinical staff used a variety of devices and approaches to ensure that they could identify patients with additional needs, for example using the Butterfly scheme. For some patients this led to dementia patients being treated with the care they needed but others reported that they weren't, with one identifying a care assistant who came across as 'brusque' with a patient. Patients on wards reported staff going the extra mile. For example, on the children's ward staff will engage with schools if children are absent for a long time to ensure that their education is not affected. However, some gave suggestions about how things could change to make it more appropriate for them, like using less clinical language when discussing treatment to make it more understandable to the patient.

Services were convenient and met their needs. There were some accessibility issues reported, particularly for wheelchair users.

Examples we identified

Care that is adapted to the individual's needs was identified as a key component in feeling that they are recognised as a person. This means recognising the accessibility issues surrounding a service and ensuring that care is delivered in a language and a way that works for their users.

Being given an active role in one's care

Being given an active role in one's care

Care home residents felt they had an active role in their care when they were able and encouraged to make choices. Food was important, with Enter and View representatives reporting one example of a non-communicative resident still being given the opportunity to choose, as was

activities, washing, bedtimes, and clothing. One relative shared that a resident had been motivated by staff to become mobile again. Many felt that they were able to seek help from staff when it was needed. However, at times residents were placed into situations where they needed help due to how carers had provided for them. For instance, chairs in one lounge were set up in such a way that for those



with walkers or wheelchairs they would need to seek assistance to be able to watch tv.

Hospital patients felt comfortable asking questions and were communicated with well. Patients were encouraged by staff to make decisions for themselves.

Patients reported that they worked alongside doctors to achieve good outcomes - "we decided what to do together".

Examples we identified

Not all users will be able to be as active in their own care but care homes provided examples of residents being supported in ways that worked for them. Individuals should be encouraged to make decisions themselves, meaning that it must be easy to communicate with those in charge of their care.

Feeling included and involved in one's care

Care homes that supported this often did so by including relatives, not only in care but also in the day-to-day activities. Residents were encouraged to take part in conversations and play an active role in their activities. One care home also reported that their staff regularly reviewed care plans with residents, ensuring that if their needs changed they were addressed. Others, however, failed to ensure that residents were aware of their choices or the decisions that they could make.

Patients reported feeling included in their treatment plan, along with relatives when appropriate. Staff talked through options and treatment.

Patients reported being involved in the decisions and plans for resolving medical concerns and needs.

Examples we identified

Including users in their care can be as easy as discussing treatment plans and options with the individual. This must be appropriate to the user's needs but should also involve their relatives or carers if possible.



Being informed about their care

Some care homes used bulletin boards with pictures of the staff and details of the activities available. Others used projectors to show pictures of what residents had been involved in over the previous weeks.

A patient in hospital reported "the Doctors don't help themselves; they didn't explain my condition to myself or family, and no explanation of the next step with my treatment. I have no information on what is going to happen to next". However, others felt that clinical staff talked with patients, explaining their treatment and informing them about what was being done, and this was supported by observations.

Patients were "helped and informed" by staff.

Examples we identified

What has happened and what will happen can be intimidating and confusing for users of health and social care. Services that enable patients by giving them information help to keep them informed and involved in their own care.



Provision for Dementia in Telford & Wrekin

We used both our Enter and View reports and a provider survey to identify examples of provision for those living with dementia, and their relatives/carers, in Telford and Wrekin.

Enter & View Reports

Several of the reports were conducted with the aim of understanding how those living with dementia can be best supported to live the best life that they can.

These, along with our other visits, offered examples of practices being used within services that could support those living with dementia.

One care home offered their residents a projector, which they had been awarded on following a dementia leadership course, that showed them photos and videos of the activities they had been on. Care homes provided for those with dementia and their loved ones by using clear and

Sensory Equipment for Dementia

These provide sensory stimulation for those living with dementia. It can help to improve their mood through distraction and entertainment, and can also help to reduce stress.

dementia-friendly signage and blue toilet seats as well as sensory items aimed at providing distraction for those living with dementia, including twiddle/fiddle cushions.

On visits to the hospital we identified the use of the Butterfly scheme, and information boards that offered information about the patient and their needs.

The Butterfly Scheme

This is a scheme running across some UK hospitals. It aims to support those in hospital living with dementia or memory loss. Staff will understand their individual needs better and ensure they remain comfortable in an unfamiliar environment.

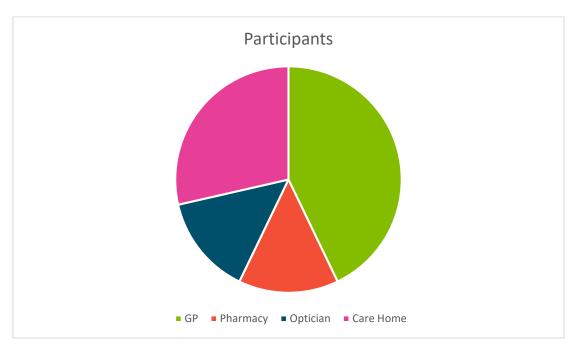




Provider Survey

Unfortunately, we did not get a high response rate for our provider survey. Despite sending it to local providers twice a total of 7 responses were gathered. As a result the findings were analysed as cases rather than as representative of local provision.

Participants



Dementia Training Provision

Care Homes

Both care homes have done awareness training e.g. Dementia Friends and Living with Dementia. One also reports that their Manager is currently completing leadership training in order to train staff.

GP Practice/Services

Two of the practices had done awareness training but one reported that it had been around two years since they had done it.



Pharmacy & Opticians

The pharmacy had provided training but the opticians had not.

Environment Provision

Care Homes

Both care homes provided information and offered signposting to those living with dementia. Dementia Friends posters were displayed by one.

GP Practice/Services

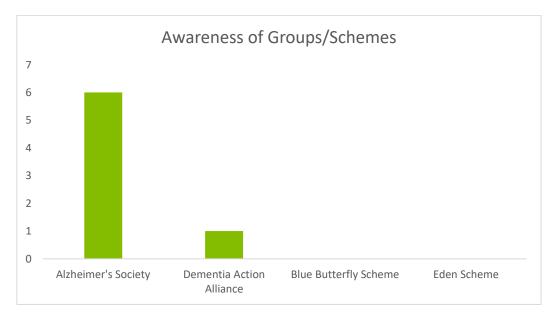
All three offered those with dementia and their relatives/carers information and signposting but none had made changes to the environment to make it more suitable.

Pharmacy & Opticians

Neither service displayed information or offered signposting but the pharmacy reported changes to the layout to make it more suitable for those with dementia. Both offered quest areas.

Awareness of Groups/Schemes

Four groups/schemes were identified in the survey. Not all were known to the providers that responded.





Supporting Customers with Dementia

Care Homes

One reported that because they do not have anyone with dementia that they do not offer services. However, they felt confident that if this were to change they would contact a community nurse for advice and look to gain as much information before the individual arrived with the intention of treating them as an individual and putting a person-centred plan into place. The other care home reported offering assistance with attendance of appointments, with or without family members. They also felt that team members could support them in understanding the results and outcomes better. Those entering the service are also encouraged to share information so that a person-centred care plan could be created, "ensuring all wishes and values are maintained and promoted". One care home indicated that they are able to access services and therapies, as well as seek external advice on products and care-aids, so as to provide for individual's needs. The other did not offer these.

GP Practice/Services

Only one practice reported that they had procedures in place. All offered additional services, including online appointments and text reminders, as well as longer appointment times and Dementia Care Planning support and review. One indicated that patients living with dementia were flagged on the system so that the admin team knew to support them. In terms of the support available, one of the services declined to answer whilst another recognised that there was a need for more targeted support for their patients. One practice offered visits at home and leaflets with information about products and care-aids. The others were unsure.

Pharmacy & Optician

The pharmacy reported offering video training to staff so they could spot signs and how to support their customers, including "patience" and offering extra time to



them. Large clear signs also help their customers in finding what they need. The opticians felt confident that their optometrists were "skilled at recognising the special needs of patients presenting with varying degrees of dementia". They also tailored their appointments to those needs including with extra time and felt they had a "very caring and friendly support staff". Visual recognition and negotiation of their environments was considered important and they reported inclusion of carers in ensuring that their patients were well cared for. They also reported that opticians are currently reviewing how services can provide for those living with dementia. Whilst the pharmacy did not offer information about products or careaids, the opticians reported that they offered magnifying device and spectacles.

Involving People Living with Dementia

Care Homes

One indicated that this was not applicable (the service who previously identified that they had no residents living with dementia). The other care home stated that they used the 'This is me' booklet which "is all about the person and helps provide a personalised approach".

GP Practice/Services

All three skipped this question.

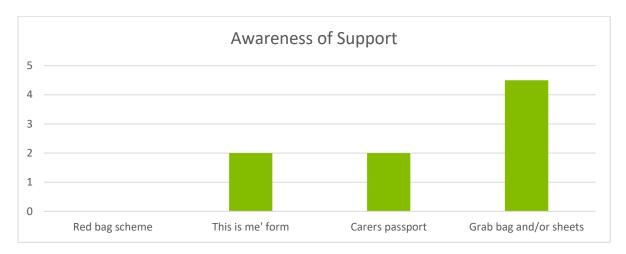
Pharmacy & Opticians

Both felt that this did not apply to them.



Awareness of Support

Neither the pharmacy nor the opticians were aware of these. More surprisingly, two of the GP practices skipped this question.



This is me

From the Alzheimer's Society this form is a support tool aimed at enabling personcentred care. It records who the person is, with details about their lives and what they like to do. It shows those who are caring for them who they are as a person but also how they like to live their lives. It can be used in most settings, whether at home or when being cared for by a service.



Discussion and Recommendations

People in Telford and Wrekin supported us in identifying three key themes with five sub-themes.

- Being treated with respect
 - o Feeling that their privacy was maintained
 - Being cared for by those who care
- Being recognised as a person
 - o Being given the personalised care that they needed
- Being given an active role in one's care
 - o Feeling included and involved in one's care
 - Being informed about their care

These themes proved to be useful in exploring the Enter and View reports in light of both dignity but also in how providers are delivering services that best the needs of those living well with dementia.

It is clear that there are many examples of dignity in care but unfortunately, there are also examples where services have failed in their delivery. We recognise not only the pressures on health and social care services but also the impact on their users, particularly those who are vulnerable. By identifying the small changes that can be made we feel that it can have a huge impact on the lives of those using these services.

Recommendations

- Services should utilise mystery shoppers; dignity champions; carers views and other local, low-cost resources to evaluate how people's dignity is being respected.
- 2. Matrons and managers should ensure staff appraisal includes dignity and respect awareness and implementation. Recognition of the role that staff



- have in patients' experience of dignity in their care and treatment is essential and examples of best practice should be acknowledged and shared.
- 3. Services should provide training and support to ensure that both clinical and support staff are comfortable with the work they are asked to do and feel confident. Dementia, dignity and customer service training can give staff the tools to communicate better with the users of health and social care services.
- 4. The use of tools in ensuring one's dignity should be considered. Tools can include aids such as dignity screens but can also mean the use of forms to request sensitive information. Providers should consider some of the examples shared in our Enter and View visits.
- 5. Commissioners should address local need for more privacy. Many of the services were unable to provide even a basic level of privacy. Whilst this is the responsibility of individual providers it is advised that commissioners across both health and social care should consider it a key provision.
- 6. Including people in their own care did not appear to be well-recognised as either an aspect of dignity or of dementia care. Promoting an individual's dignity, informed choice and ensuring good practice been a driving force in health and social care provision and must be addressed not only at the provider level but across health and social care delivery at all levels. Understanding what informed choice looks like and how it can be delivered should be a key priority, particularly as services skipped questions in the provider survey regarding, 'involving people living with dementia' and 'awareness of support'.
- 7. Additionally, local services could include and liaise with carers and families where appropriate and possible in order to support inclusion of the person living with dementia and promote support and awareness. Family involvement has been important for people living with dementia, as they can advocate for their relative particularly if the person living with dementia cannot clearly communicate their wishes.



- 8. Front-facing areas such as GP receptionists or pharmacies need to systematically consider people's dignity through finding ways of communicating with people that especially maintains privacy and confidentiality.
- 9. HWTW to propose working with GP practices in developing a Dignity "chartermark" for reception staff.
- 10. Dying/death/end of life is an area that must be treated sensitively and is often not addressed directly in service provision. Further exploration into how local services can promote dignity in death could be somewhat reassuring for those who have life threatening illnesses, and their families and friends.