

# The PIECE-dem observational process

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*Manual version 3*

*Guide for Researchers and Practitioners*

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## Introduction

The development of this process was funded by The Department of Health's Policy Research Programme (PRP) and Comic Relief as one of a number of projects making up the PANICOA (Preventing Abuse and Neglect in Institutional Care of Older Adults) research initiative. For further details of this initiative go to [www.panicoa.org.uk](http://www.panicoa.org.uk)

This process was developed within the 'How can I tell you what's going on here?' study. The study's aims were to design an observational tool that can identify risk factors for abusive, neglectful or disrespectful care and also identify protective factors associated with supportive, nurturing and respectful care. The observational tool is designed to capture the experiences of people living with dementia in care homes who are not able to tell us directly about their experiences due to the nature and severity of their disabilities. It particularly focuses on those who are most vulnerable, for example because they have little or no verbal communication abilities, they are cared for in bed, are very agitated or judged by care staff as presenting very high levels of 'challenging behaviour' or because they have sight or hearing loss.

This guide is developed for use by both researchers and practitioners. Different parts of the process may require slightly different planning and execution depending on why PIECE-dem is used; as part of a funded research study or by an employee in an organisation as part of practice development and care quality review. However, the principles and overarching guidance are applicable in both situations. Whether researcher or practitioner, an understanding of the advantages, pitfalls and appropriate practice of observation will enhance the outcomes of using a tool such as PIECE-dem. In addition, a solid understanding of person centred care for people living with dementia is essential for anyone using PIECE-dem.

## The PIECE-dem theoretical foundation

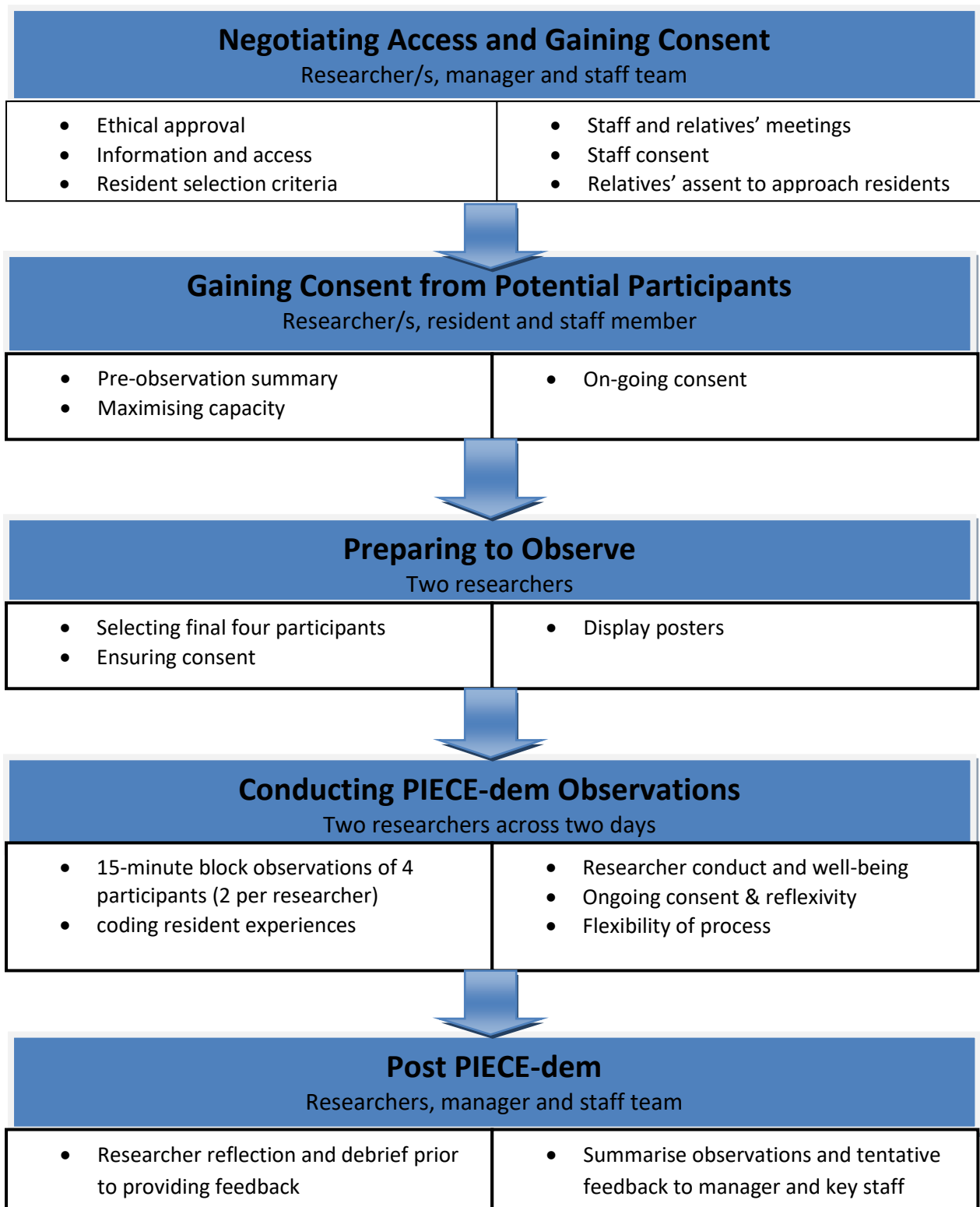
The PIECE-dem observational tool is designed to help capture the care experiences of people living with advanced dementia in care homes. It can be used to audit these care experiences and explore potential improvements to care provision, or it can be used as part of a broader research process, in which the experiences of those with advanced dementia are a central tenet. This manual details the entire process of using PIECE-dem: achieving access, gaining consent from all involved, conducting observations, interpreting results and providing feedback. Central to the use of PIECE-dem and the insights it can provide, is an understanding of the theoretical foundation from which it emerges. No researcher or practitioner should seek to use PIECE-dem without an understanding of this. The observations made throughout PIECE-dem, and analysis of the whole dataset for each individual observed rely on the interpretation of observations by the researcher/practitioner in light of the coding framework which is rooted in this theoretical foundation.

At its core, PIECE-dem recognises that well-being for people living with dementia is achieved through person-centred care practice as described extensively by Kitwood, (1997), in “Dementia Reconsidered: the person comes first.” Person-centred care, emphasising relationships, communication and the development of a positive social psychology for the person living with dementia, helps to maintain personhood in the face of declining mental powers. Therefore, care experiences exhibiting such characteristics would enhance well-being of a person living with dementia. Conversely, in environments where care does not exhibit person-centred characteristics, personhood is undermined and as such care experiences of individuals may enhance ill-being, and in certain circumstances extend towards abusive and neglectful practice.

It is therefore recommended that any person undertaking to use PIECE-dem should fully understand the concept and reality of person-centred care as it relates to people living with dementia. Further detail as to this theoretical foundation and the development of PIECE-dem can be found in the report “How Can I Tell You What is Going on Here? The development of PIECE-dem,” (Brooker, De Vries, La Fontaine & Porter, 2010). The PIECE-dem framework for coding resident experience is outlined within this manual (see page 28) and this provides information as to the type of indicators of positive care experience and risk factors for abuse and neglect to which PIECE-dem is sensitised.

## The PIECE-dem Process

The different stages of the PIECE-dem process are outlined in Fig. 1 below and discussed in detail throughout this manual. They may manifest differently for a researcher or practitioner (for example, whether access negotiation/ethics process is through a formal ethics committee or organisational processes). However, each stage is essential to consider within the context of role, setting and rationale for using PIECE-dem.



## Setting up the observational process: letting people know what is going on

Setting up the process and informing all who are likely to be involved, is an integral part of the PIECE-dem process, enabling informed choices to be made by all involved, and creating opportunities for a collaborative process to begin. This collaboration ultimately results in positive care practice being recognised and valued, and action plans to address areas of development to improve care practice. Whilst a researcher/practitioner can often be anxious to begin data collection it is important to recognise that gaining access, providing information and ensuring informed consent are essential steps not only in maintaining ethical practice, but also in terms of getting the best from the PIECE-dem tool.

It is therefore important that everyone in the care environment is aware of what you are doing when you are conducting PIECE-dem observations, so that all those present during the observation period are able to make a choice about their participation/presence. The purpose of PIECE-dem makes it particularly important that this process is followed rigorously. Staff, residents and relatives are likely to experience significant sensitivities about the process and what it might reveal. Consequently you will need to be open and honest about the boundaries within which you are working, your obligations and the obligations of the organisation you work for in regard to safeguarding of vulnerable adults.

The following section details what you need to do to ensure that information about PIECE-dem and your work in the home is made available to everyone who may need it, and that you have achieved consent where this is required. It is important to be sensitive throughout this stage to the ways in which different organisations operate and flexible in your approach so as to maximise opportunities to share information about the PIECE-dem project.



## Negotiating Access and Gaining Consent

*Note: this is the stage in the process that will differ most between a researcher and practitioner using a tool. Both researchers and practitioners should investigate fully the guidance within their own organisations for processes to be followed.*

### **Stage 1: Ethical Approval**

The first stage of gaining consent involves ensuring that you have achieved appropriate ethical approval from the relevant local ethics committee before approaching the organisation/care home. Part of the process of achieving ethical approval will involve the development of information sheets for the organisation, for staff, for residents' relatives and for the residents themselves.

For a practitioner, you should consult your own organisation to consider any formal ethics process to be followed, as these can differ depending on type and size of organisation. Developing ways of sharing information and considering approaches to consent will still be important, regardless of the ethics process in place.

### **Stage 2: Making Contact**

Having achieved ethical approval, make formal contact with the Manager/Owner/Organisation through a covering letter/e-mail and information sheet explaining the research study. The aim should be to arrange an informal face-to face meeting to explore the research further with the home manager. It is important not to underestimate the time needed to achieve this, and to anticipate in advance the various concerns that Organisations and individuals may have about your proposals. Be prepared in a face-to-face meeting or a telephone call, to explain the process in detail and the importance of consent at all levels. Be prepared for the possibility that the organisation may need to go through various procedures before giving agreement to participate.

Making contact may be more straightforward as a practitioner, but taking time to discuss the purpose and process with the senior staff is still important.

### **Stage 3: Informing and Gaining Access**

Once approval has been achieved, your next step should be to arrange to meet with the manager and, if possible, the senior care team. You will need to repeat the process of

explaining in detail the research study, the inclusion criteria for residents and the process of consent. It is important at this stage to be clear about the practicalities of being involved in a PIECE-dem and the workload this may present to the senior staff team, (such as the need to send out letter or flyers, organise meetings or answer questions about the research). Reluctance or inability to carry out these roles will make conducting PIECE-dem problematic, if not impossible. In addition, reluctance to carry out such roles can be a way in which individuals or organisations show lack of consent to the process, without explicitly stating it.

Once you have gained initial consent from the manager/senior staff team, you need to identify a suitable date for (at least) one meeting for staff working within the care setting and (at least) one meeting for relatives of residents within the home. These dates should be planned for at least 2 weeks ahead in order that staff and relatives are able to attend. At this point you will need to provide the following materials for the manager:

1. Copies of your information sheet for staff including the date of the staff meetings and consent forms, and a box in which staff can place their completed consent forms;
2. Copies of your information sheets for relatives of residents, including a covering letter explaining the reasons for this contact, and the date of the meeting.
3. Copies of an agreement form for relatives to complete, giving you permission to approach their relative regarding the study;
4. Stamped envelopes in which information for relatives can be sent, plus reply paid envelopes so that relatives/next of kin/advocates can return the agreement form to you;
5. Posters for display in general areas which should have your photographs on them and information about the proposed study, including the dates of the meetings.

It is also advisable to set prospective dates for the actual observation with the manager and senior care team. These dates should be at least two weeks after the dates of the staff/relatives meetings, and can be included on the display poster and in the information materials for staff and relatives. However, be aware that delays in achieving effective communication within the home, or consent from the various parties involved in the study may require these observation dates to be changed.

Again, arranging meetings and sharing information may be more straightforward as a practitioner. However, it is still a vital step and it is important not to rush into conducting a PIECE-dem without considering this step.

#### **Stage 4: Selecting residents for possible inclusion in the research**

At this first meeting, or once the manager/owner has confirmed their wish for the home to be involved, you need to discuss with the manager or a senior member of the care team the residents who meet the criteria for potential involvement in PIECE-dem observations. You want to observe people who have advanced dementia, appear unable to give informed consent to take part in the study **and** meet one or more of the following criteria:

- Cared for in their mostly in their room
- High level of falls accidents
- High levels of dependency re: communication
- High level of challenging behaviour/un-aesthetic behaviours/sexual behaviours
- Very mobile or agitated residents
- Residents with sight and/or hearing loss

From this selection of residents, you should exclude residents who appear suspicious or who currently have acute physical or mental health difficulties. Whilst you will only be observing four residents in total on the actual observation days, it is important at this stage to identify as many potential participants as possible from all the residents who live in the care home. This ensures that individuals are able to decline to take part and allows you flexibility on the days of observation to choose four residents who represent the spread of care needs and experiences in evidence at the home.

Once this selection of possible PIECE-dem participants is identified, the manager/senior care staff will need to send the information sheets, consent forms, covering letter (including meeting date) and reply paid envelopes to the relatives/next of kin/advocate of these residents. This action cannot be carried out by the researcher due to data protection requirements., but it could be carried out by a practitioner if access to this information is permitted as part of their existing role.

In addition, at this stage you should also do the following:

- Ensure all relevant staff in the home have received an information sheet (including meeting date) and consent form, including instructions on where they can leave their consent forms
- Place the staff consent form box in a visible place in the home
- Ensure that posters and additional information leaflets about the study are placed in prominent areas of the home, such as near the front entrance or signing in book.
- Discuss with managers and senior care staff the possible anxieties that research may raise for staff. This might highlight the possible need for support to be in place for staff should they need to access it.

### **Stage 5: Relative and Staff Meetings**

On the meeting dates, ensure that you have a substantial block of time before and after the meeting to spend in the home. There may be questions that people will not ask in a group meeting, but will in a one-to-one conversation. Remember to take along additional information sheets, agreement and consent forms and identify a date by which the forms should be returned, either to you directly or via the consent form box at the home.

It is likely in the meetings you have with relatives and staff that you will encounter some anxieties and concerns about the research because of the nature of the work you are proposing. The meetings should begin with introductions and a brief presentation on the research you are undertaking and what it will involve. It is important to create a clear understanding of the purpose of using PIECE-dem as well as what it is not intended to do. Both staff and relatives will need to be informed about the expected outcomes of your research. Questions should be encouraged and efforts made to engage staff and relatives in a collaborative process in which you are open and honest about your work.

For each group the following should be emphasised:

- Staff

Staff can decline to participate and it is not a condition of their work that they participate. They should indicate their consent or non-consent to the researcher/s through the use of consent forms. They do not have to give a reason for their choice to either the researcher/s or their manager. If they choose to decline every effort will be

made to ensure that, during the time of the observations, they are either: not observed; off duty; or in a different area of the home to where observations are taking place.

- **Relatives/advocates**

Relatives/advocates are not being asked to be participants to the study, but they are being asked for their agreement for their relative/resident to be approached about the research. Due to the focus of PIECE-dem, residents who would be able to easily consent on their own behalf are unlikely to be participants. Whilst a relative or advocate cannot consent or decline on behalf of another person, it would not reflect good person-centred practice to ignore their concerns should any be expressed. Using PIECE-dem should not interfere with the quality of life of the person living with dementia and conduct PIECE-dem without considering (or actively going against) the wishes of people close to them could have long term negative consequences for the person's quality of life and relationships in the care setting. Relatives/advocates can refuse to give agreement, and do not have to give a reason either to the research team or the home's staff. In some circumstances, it may be that their relative will be in the vicinity of observations when they do take place and so it is important to highlight observer sensitivity and response to apparent distress or anxiety caused to any resident during observation periods, (whether the focus of the observation or not) .

### **Stage 6: Confirming and finalising observation dates**

Following the final date for staff/relatives to return their consent or agreement forms you should arrange a brief meeting with the manager. This is to establish which staff have consented to take part and enable the manager to consider their staffing arrangements on the days of the observation according to this information. If appropriate, you can also begin the process of consent with potential participants living with dementia on this day as well, as outlined below. Otherwise, you should arrange a time to visit the home for this purpose.

In the event that at this stage you do not appear to have sufficient staff consenting to take part, you should consider whether it is appropriate to try other methods of raising awareness of the research amongst the staff team. Sometimes it may take several meetings or one-to-one discussions for staff to get to know about the research and researchers and explore what it means for them. However, it is important to ensure that these additional

efforts do not pressure staff into taking part and to remember that, for some, choosing to disengage from information sharing processes is a way to indicate lack of consent. As such, if there is insufficient staff consent you should also consider whether withdrawing from the home as a research site at this stage is the more appropriate course of action.

*Note on agency staff in care homes:* If the care home in which you plan to undertake observations uses non-permanent members of staff, (employed via an agency on an ad-hoc basis) you should carefully consider at the outset the impact this may have on the practicality of research in the home, particularly if their use is a substantial feature of the home's staffing arrangements and they are likely to be present during observation days. It is unlikely that you will be able to engage agency staff in the formal awareness raising and consent processes outlined above and to subject these staff to on-the-day consent seeking would be unethical due to the insecure nature of their employment arrangements with the home.

### **Consent with people living with dementia who are resident in the home**

Once consent and agreement have been gained from staff and relatives of potential participants, you can then begin to approach the potential participants living in the home about the research. The issue of consent is particularly important to consider when conducting observation where people with dementia will be participants. In developing the consent process we have drawn particularly on the work of Allen (Allen 2001; Killick and Allen 2001), Dewing (2002) and our own considerable experience in conducting research with people with dementia. The consent process also takes into account the implications of the Mental Capacity Act (2005) to practice in England and Wales. You will be the principal person involved in obtaining consent, but should work together with staff and people who know the person well.

From a person-centred perspective gaining consent from people with dementia to participate needs to be a meaningful and inclusive process that takes them seriously as capable persons (Dewing 2002). We intend that the consent procedure is seen as a process rather than a one-off event, with individuals being given information on a repeated basis, and a sequence of opportunities being provided to withdraw if this is their wish. In addition,

it takes into account that people can communicate their wishes through behaviour and body-language as well as through verbal communication. Gaining consent for the PIECE-dem observations in your research will therefore be a four-stage process.

**Stage 1:** The first stage of the consent process will be for you to meet with the resident's key worker (or a staff member who knows them well), and where possible their relative/advocate to complete the pre-observation summary (see Fig.5 ). This should only be completed on those residents whose relative/advocate has indicated agreement for you to approach them. The pre-observation summary will assist you in understanding how to approach the resident and assess for signs of ill-being or well-being while you are talking with them. This will help to inform the decision you make.

**Stage 2:** The next stage is gaining formal written consent to take part. Although capacity to consent is defined in the Mental Capacity Act (2005) as a process that requires individual assessment of capacity for each decision to be made, the inclusion criteria for PIECE-dem specifically seeks potential participants who have advanced dementia and are therefore highly likely be unable to provide fully informed consent. However, this does not exclude the potential participant from the consent process. Furthermore, you should not assume the resident cannot give consent; capacity to consent should still be assessed as you give information to the resident.

When seeking consent, you should be accompanied by a staff member who knows the person well and/or relative/advocate of a potential participant, as this will help to interpret a person's verbal and non-verbal communication. It will also be helpful to discuss your thoughts/opinions on the person's participation in the event that it appears they cannot give informed consent. This capacity judgement, and subsequent decision-making if the person does not seem able to consent, should involve talking to the person and assessing their reaction to an explanation of the PIECE-dem observations or to your presence. By having another person present, unconnected to the research or practitioner plan, ensures that the needs of the research do not override the interests of the potential participants.

When seeking consent you need to have a conversation with the potential participant. This should take place at a time when the resident is most likely to be able to concentrate. You can provide them with a simple information leaflet about PIECE-dem to support this

discussion. You need to check with the potential participant that it is okay for you to spend some time with them talking about the planned observation and, if this seems acceptable to the individual, move on to discuss the PIECE-dem process. You should be mindful to pitch your explanation at a level likely to maximise a person's chances of understanding. For example, the phrase 'I want to watch what life is like for you' may be more appropriate than 'I wish to conduct observations of the care you receive'.

During this conversation you should ensure that you provide plenty of time for the person to respond to you and that you are attentive to a person's body language and facial expressions. You should also make sure to explicitly ask a person if they would like to take part. If the person shows any signs that they are not comfortable with your presence or with the discussion, then you should accept this as a possible refusal of consent and withdraw the person as a potential participant.

If the person does not appear to be expressing unwillingness or anxiety about the idea of participating, or with your presence, then the member of staff or relative needs to confirm this assessment and provide any further information on whether they feel this is something the potential participant would be happy with based on their knowledge of the person. In the event that both you and the staff member/relative agree that a person appears to be showing assent thus far, this should be recorded and signed on the consent form.

**Stage 3 :** At stage three you will have a reduced pool of potential participants made up of those who originally met the inclusion criteria, whose relative/advocate agreed for them to be approached, and who themselves did not appear to show anxiety or distress at discussion of the research. For this group, stage three refers to any subsequent conversations or discussions about the observation process and is an ongoing consideration of the person's willingness to continue their involvement. Each time a period of observation is undertaken involving the person, you should reintroduce yourself to the participant and remind them what you are doing. You need to satisfy yourself that they are happy to still be included before you begin your observations. If they do not appear happy or willing at the prospect you should not observe them. In these situations, you may have other participants who you could consider observing instead.



In the event that a participant is asleep or involved in an activity important to them at the start of an observation period it would not be appropriate to disturb them (or others) in order to confirm assent to being observed. In these situations you should approach the person as soon as possible after the event to seek consent and, if they appear to withdraw consent, disregard your observations from before this time.

**Stage 4:** Throughout the PIECE-dem observations you should assess continually that being observed is not causing distress to the resident. Should you feel that observing a resident is causing them distress, anxiety or affecting the quality of their care/experiences, you must stop observing them immediately. In addition, you should continually consider the impact of your presence on others present in the area and in the event that your presence is causing distress, stop observations in that area immediately. You may have alternative areas in which you can observe, but this will not always be the case. In the event that observations are stopped due to resident distress, you should ensure that appropriate measures are employed to alleviate any distress in residents.

## Preparing to Observe

*Once observations start, both researchers and practitioners become 'observers' and so this term is used in the following passages.*

### Selecting participants to observe on the day

On the first day of observation you will need to select which four residents you and your co-observer will observe during the two-day observation period. If you have more than four residents who have consented to observations taking place, then you should select four to reflect the range of inclusion criteria for example: mobile and immobile residents; residents with and without sensory impairments. You should also try to include one resident who is seen as 'challenging' and one who is seen as 'quiet'. Depending on the care home in which you are researching, you may also want to consider selecting participants to reflect particular features of the home, such as residents being cared for in different 'units' or by different staff groups in the home.

You should then follow stage three of the consent process for participants living with dementia to make sure that each participant is still happy for you to conduct observations of

them that day. If they are not, another participant should be selected. If they are, stage four of the consent process should be followed throughout all observations.

### **Preparing the observation process**

When you arrive to carry out your observations on the first day, you should swap the posters on display for new ones which inform residents, staff, visitors and relatives that you are present in the home and what you are doing there. This should include photographs identifying you and your fellow observer. You will need to negotiate with the manager a private space that you and your co-observer can use during your breaks.

Having completed the selection of the residents to be observed, you should take time to inform staff about your presence and remind them of your role in the home. You should also do this with any relatives and visitors who are present during the observation period. It is also important to ensure that other residents in the area you are observing in are greeted and informed of your work in the care setting. Do not underestimate the possibility of staff on the day being unaware of the research, and allow yourself sufficient time to ensure adequate consent from them on the day. In certain circumstances, this may result in a decision to alter or reduce the time spent observing, (especially if this is necessary to enable adequate consent and/or to protect observer well-being). If the process of gaining staff consent is particularly onerous or impractical (see note on agency staffing page 14), withdraw from observations on this day and rearrange.

## Conducting PIECE-dem Observations

### Introduction

PIECE-dem illuminates the experience of those people who are most vulnerable to experiencing a poor quality of life in long term care settings. PIECE-dem is an acronym for:

Person

Interaction

Environment

Care Experience in **Dementia**

Prior to commencing observation you will have selected four residents to be observed in detail. As well as dementia, the selected residents should have high levels of need and have characteristics which mean they are potentially most at risk of neglectful or abusive practice. As outlined above these include those who:

- Are least able to communicate
- May be withdrawn
- May be at end of life
- Have bruising or other physical warning signs
- Are viewed to have high levels of challenging behaviour/un-aesthetic behaviours/sexual behaviours
- Are very mobile or agitated
- Have sight and/or hearing loss

The reason for focusing on this at risk group is that they have high levels of need for staff interventions which support their well-being and if the care they receive is supportive for them you can be fairly reassured that the care received by residents with lower levels of need will also be supportive. Details of how you will code resident experience during your observations is provided on page 28. However, the overall process and practicalities of conducting a PIECE-dem observation are described first.

### The PIECE-dem process

Each observer works with two participants throughout the observation, spending time with each participant in 15 minute blocks over a two-day period. The time period observed covers a typical waking day and is carried out over two consecutive days in order to capture

how different staff and teams may impact upon the experience of each participant and to ensure that observations capture the key events in the resident's daily life. This breadth of time also allows time for observers to reflect on their observations of residents, and upon their own experiences, ensuring reflexivity and researcher well-being.

As a general guide, observations should take place between 1pm and 9pm on day one and 8am and 1pm on day two, (see fig 2). During this time observers alternate between the two participants they are observing and incorporate time for their own breaks. However, the two researchers conducting observations should be mindful of two issues throughout their observations and this may result in an alteration of these timeframes:

- The purpose of the observations is to maximise the resident experience observed, and this will mean differences in what a 'typical waking day' may mean for each participant, (for example, if a resident does not wake up until 10am, but goes to bed at 10pm, it may be necessary to observe these as start/finish times). Therefore, the framework can be altered to capture these experiences providing it does not interfere with researcher well-being.
- Observers must be aware of the intense nature of observational work, both physically and emotionally, and as such must take care of their own (and each others') needs at all times. If it is necessary to shorten the observation periods, to spread them out across an extra day, or to meet more frequently during the observations, then this is possible, (see 'flexibility of process' for more detail). Due to observer fatigue it would never be appropriate to attempt to complete the whole observation in one day.

During the observation process you will make observations of the participants' experiences of the world around them, using 1-minute time frames. This will include recording the following:

- If the person appears engaged with or disengaged from with the world around them;
- If an interaction occurs;

- Qualitative notes describing the person's apparent experience of the world around them, what their needs might be, the nature, intention, and experience of interactions and the extent to which apparent needs are met.
- Qualitative notes describing the immediate environment within which the resident is spending their time, which includes the extent to which the environment appears to support the physical, psycho-social and spiritual well-being of the resident.

Your observations of residents will occur in public areas and in hallways. As PIECE-dem tracks an individual's experience of care, some observations are undertaken in or immediately outside the person's room. This is particularly the case if the resident is spending long periods in bed or is bed-bound. However, when observing in a person's bedroom, researchers should be mindful of the need to be unobtrusive and to ensure consent of the resident. This is discussed further in 'Observer Conduct' below.

Intimate care activities should not be directly observed, but how residents are escorted to the bathroom following an episode of incontinence, how they appear following intimate care delivery, or how people are helped to eat a meal will often be very telling about how more intimate care might be given. Observation periods should include times of high demand for staff interventions, (such as mealtimes and high levels of need for personal care), as well as reflecting the individual resident's routine and level of activity. Therefore, as indicated in the time framework for observation, (fig 1), break times are planned to avoid key times of interaction/ activity for residents. Again, as outlined above, the time framework for observation can be altered to reflect the routines of the participant or home in which you are observing.

Observations are summarised every 2-3 hours for each resident. By the end of the two days, you will have achieved approximately four hours of observation for each resident and, as a result, have up to 16 raw data sheets (see fig 3) and 5 observation summaries (see fig.4) for each participant. The raw data sheets and summaries will form the basis of your research data and the summary sheets in particular will form the basis of your feedback sessions to the care team. It is important that you allow sufficient time in the days following an observation to adequately consider the data collected. This is because data written 'in the

field' may make less sense to the researcher if this is delayed and there is a danger of misrepresenting or misinterpreting the data.

### **Observer Conduct and Well-being**

Observation has the potential to be intrusive and to cause worry or distress. It is therefore extremely important that you are mindful of your own conduct during the observation process to minimise disruption to all concerned. When in the care environment you should be a role model of good practice to staff and always remember to treat everyone in a person-centred manner. In addition, observation can be physically and emotionally intense for the observer, and as such you should be mindful of your own needs throughout the observation process.

### ***Unobtrusive observations***

You need to ensure that you are as unobtrusive as possible during observation. Therefore, do not take things you do not need into the observation area with you. Take the papers you need, a pen/pencil and a timekeeping device if necessary. It is always helpful to carry some extra coding sheets and a spare pencil so that if a resident wishes to write alongside you, you can offer them some papers and a pencil. If you take bags, coats and other things into the area with you will look more obtrusive carrying them and they are likely to be appealing to residents who may want to look in them or take them away. This may be the case particularly in environments where there are few other objects and items for engagement. It is also inadvisable to take valuable items with you into the research area for the same reason.

Where you position yourself in the room is also important. You are observing in areas in which people live and they may have their own routines and personal preferences. Sitting in chairs that are used by residents may be problematic, particularly in small spaces where all available chairs are used by residents. Positioning is also crucial in regard to the experience of the resident you are observing. Residents are likely to be aware of your presence. Being observed for 15 minutes at a time can be quite intense, so consider how you observe them, and monitor their reactions to your observation.

Observation of residents includes (where appropriate), following them at a discreet distance into the hallways and other areas of the home. However it would not be acceptable to be

present when the resident is receiving intimate personal care. During these occasions, it may be appropriate to stay near their bedroom or bathroom and discreetly observe their reactions prior to and after they have received care. If a resident moves around a lot, you may have to consider when to follow them, or where to sit in such a way that you can observe them unobtrusively during the period of observation.

### ***Observing in bedrooms***

Some participants you observe using PIECE-dem will be bed-bound and may be being cared for in their own room. If this is the case then it may still be possible for you to carry out observations. However, if you do so you should ensure the following:

- This is not upsetting for the person;
- You can remain 'unobtrusive' in the sense that your presence does not significantly affect what you are observing.
- No personal care is being carried out;
- The person does not have visitors;
- Your observation is not off-putting for a staff member or the participant, for example causing the person to behave differently e.g. putting them off eating.

### ***Responding to interaction***

You need to remember that you are a role model of good practice. Therefore, it would not be appropriate for you to ignore anyone who wanted to talk to you in the care environment. When carrying out observations, as well as being prepared to answer questions yourself, you should always arrange for a member of staff who is working during the observations to be available to answer any questions from relatives or visitors. Residents, including the person you are observing, may want to interact with you, particularly because you are present in the home for long periods of time. It is important to engage with questions or conversations while trying to maintain a balance with the purpose of your work in the home. For this reason, during selection of potential participants for PIECE-dem, it is important to consider the practicality of observation for particular residents. If it is clear that they will wish to interact with the researcher for significant periods during the observation, (or this turns out to be the case once you commence observation), then they would not be an appropriate participant, as it will be impossible to achieve a balance between observing and interaction.

*Mimi was identified as meeting the PIECE-dem criteria by her care home. Her daughter agreed for her to be approached about taking part in the research. In her pre-observation summary it was noted that “Mimi calls out to anyone who passes by her room, because she likes to chat and have one-to-one time.” When the researcher met with Lily, she said that she’d like to be observed as it was nice to have someone to chat to. The researcher also observed that Mimi would call out to anyone she could see nearby. The researchers concluded that, whilst Mimi appeared happy with the idea of being part of the research, it would be impossible to observe her unobtrusively as Mimi would wish to interact with the researcher on a frequent basis.*

Our experience of observing with PIECE-dem is that it is likely that you will, on occasions, need to engage to some degree in what is going on around you, particularly in smaller lounge/dining areas. For example, if there is a group activity occurring, such as singing or exercise, it may be appropriate to have some involvement in this. In effect, engaging in the environment to a limited degree can actually help the observer to remain unobtrusive. You will need to reflect and monitor your impact upon the residents and the environment and adjust your position/behaviour to achieve a balance between your observation and the participation necessary to remain unobtrusive and person-centred in your approach.

### ***Safeguarding adults from abuse and neglect***

Prior to commencing the PIECE-dem process, you should ensure that you are familiar with your responsibilities concerning safeguarding in the local authority area in which the home is based. Your responsibility to ensure that the well-being of residents is upheld is paramount and should you witness any action which causes you to be concerned about the welfare of a resident/s, you are obliged to respond according to the local policies and procedures. Should you witness, for example:

- Action or inaction that causes the resident to be at risk of harm or experience harm
- Long periods of unattended or admonished distress
- Unauthorised deprivation of liberty



You will need to cease observations, consult with your co-observer immediately and agree an appropriate course of action. In the event that something occurs which requires your immediate intervention to ensure the safety of a resident, then you should take that action and seek further help from staff. It is important to make a note of these actions within your observation notes to explain why your observations were halted and to aid researcher reflexivity on a resident's care experience.

*Lily was sitting in the lounge in front of the television. It was evening time and a member of staff was in the room but attending to another resident. You were observing Lily when she looked at you and spoke to you and then tried to get up to walk over to you. Lily seemed unsteady so you got up to support her, and asked her if there was something she needed. You continued to talk with her until the member of staff was able to join you and take over and it was appropriate for you to withdraw.*

### **Observer well-being**

It is vital not to underestimate the physical and emotional impact that conducting PIECE-dem can have on observers. As well as having responsibility to avoid harm for participants and others in the setting, you also have a responsibility to avoid harm to yourself and your fellow observer and to comply with the working practices and regulations of your own employing organisation, (particularly with regard to working hours). You should ensure you have sufficient support in place prior to commencing the PIECE-dem process, particularly if you are unfamiliar with care home settings. A researcher who conducts observations in a care home without being fully prepared or without support for and awareness of their own needs, runs the risk of not only causing themselves harm, but also causing unintentional harm to the setting and participants.

PIECE-dem particularly addresses observer well-being in the following ways:

- The use of two observers

Having a co-observer present in the setting allows for researcher reflexivity, support and discussion around urgent issues such as a safeguarding concern. It would never be appropriate to attempt a PIECE-dem without a co-observer.

- Periodic observer meetings throughout the observation

The framework allows for the observers to meet for at least one hour on five occasions across the observation period. Meetings should never occur less frequently than this, and can occur more frequently (or last longer) if required, (even if this results in less observation

data). These meetings are an essential part of the observation process and as such should be treated as sacrosanct by both observers. Time and place for meetings should be agreed prior to starting observation and both researchers should stop observations in order to meet their co-observer in a timely manner.

### **Flexibility of the PIECE-dem process**

Whilst the observation framework is set according to what best achieves the intended outcomes of a PIECE-dem, flexibility in the practicalities of the process is acceptable if it is to respond to one of the following four issues:

#### **1) To maintain observer well-being**

*In Beeches Care Home, the observers found they needed additional time to meet together, due to the complexity and difficulty of what they were seeing. Therefore less observation time was available. In addition, they agreed to finish one hour early, as they were tired following the intensity of what they had observed.*

#### **2) To maintain the well-being of a group of residents/staff**

*On day two of observations at Brierley Care Home, a group of staff attending training were sent to observe in the same area as the researchers. The observers halted their observations for the day (and returned several days later) because it was felt there were too many people in the lounge, and this was distressing residents and making care tasks difficult.*

#### **3) To respond to the routines of the home**

*Staff at Fairview Nursing Home change shift at 1.00pm. In order to capture the impact of this handover period, the observers decided to start their second day of observations at 12.30.*

#### **4) To better capture the care experience of a participant**

*Towards the end of a 15 minute observation of Peter, a member of staff approached him in order to engage him in an activity. The observer felt it was important to capture this experience of Peter's and so it was decided to continue observing for a further 15 minutes, providing Peter and the staff member did not show discomfort. Following this double (consecutive) observation, the observer observed her second participant for a double period as well.*

However, any flexibility employed should ensure not to violate the following principles of ethical practice:

- Ongoing consent of all involved
- Avoiding harm to participants, staff, other residents, visitors and researchers.
- Awareness of the impact of observation on participants
- Being open and honest about the purpose of your research
- Using PIECE-dem on residents other than those who meet the selection criteria; it is not validated for that purpose.

## Coding resident experience

### Person, interaction and environment

The focus of this observational process is to try to understand the experience for the person living with dementia, of the world around them and the extent to which it supports their well-being. The PIECE-dem process has been developed through analysis of literature, in-depth interviews and focus groups and subsequently supported by detailed observations of the experience of people living with dementia who have significant levels of need, and reside in care settings. Through this process it has been identified that there are a range of indicators of positive, person-centred practice in which the person living with dementia receives care which appropriately supports their psychosocial, spiritual and physical needs (Table A).

**Table A: Examples of Indicators of Positive Person Centred Practice**

Person	Interaction	Environment
<b>Uninhibited Behaviour</b> <i>"I think bursting into song is one thing that you sometimes experience with some people, that's not going to happen when they're not feeling comfortable."</i>	<b>Knowing the Person</b> <i>"I watched a member of staff come into the room with a gentleman who liked a particular sort of music, she went over to the stereo, put a record on that he liked, and danced with him and she danced with him to the toilet"</i>	<b>Environment supportive of needs</b> <i>"The layout of the environment is really supportive of this (residents interacting with others), no chairs lined up round the walls, chairs in clusters which facilitate interactions together"</i>
<b>Not Withdrawn</b> <i>"Well withdrawal is the big one, (wife) has come out with the right care"</i>	<b>Social engagement Staff/Resident</b> <i>"Sharing humour"</i>	<b>Environment individualised</b> <i>"Good physical environment with lots of visual stimulation; sound that is achieving something – so not having the TV on just for something for people to look, at"</i>
<b>Autonomy of Actions</b> <i>"free to move about and touch things and move things"</i>	<b>Responding to Residents</b> <i>"There is one woman there who does a lot of shouting, and when she starts shouting the care worker will go up to her and say 'right *** what's the matter?', go and sit by her, quieten her down and she's fine for another couple of hours"</i>	<b>Protective technology</b> <i>"We put sensors on his door, staff were alerted if he moved, and also on the door of the vulnerable person. That was protective"</i>
<b>Physical Care</b> <i>"hair and nails are cared for"</i>	<b>Residents Engaged with Others</b> <i>"People talking with each other and staff – it may not be a logical conversation but they are interacting with others"</i>	<b>Opportunity to engage with the world</b> <i>"It's not just about being able to see the outside world, it's about being able to access it"</i>
<b>Physical appearance well maintained</b> <i>"Appearance is appropriate for person"</i>	<b>Facilitating autonomy/freedom</b> <i>"One lady actually went out in the snow, even though staff were absolutely terrified, this lady really wanted to go out and had always go out... that's respecting that person's want to do that and it spoke volumes to me because it's not often that people would be allowed that risk"</i>	<b>Opportunity to Engage with Possessions/Objects</b> <i>"A good sign is where people seem to have possessions, it's sad that we have grasped on rummage bags and clutter but that's what we mean, things that people can touch and move that gives them a sense of purpose"</i>

It is also evident that there are a range of indicators that would suggest that the person experiences poor care, which does not meet their needs and can result in abuse, neglect and loss of dignity (**Table B**).

**Table B: Examples of Indicators Leading to a Risk of Abuse Neglect or Loss of Dignity**

Person	Interaction	Environment
<b>Unattended Distress</b> <i>"We might see distress in someone's face, the way someone is moving or the way someone is articulating and shouting, and to not acknowledge that would seriously worry me"</i>	<b>Short tempered Staff</b> <i>"A bit snappy and short tempered, she would shout 'oh shut up'"</i>	<b>Freedom to Move</b> <i>"All the residents are in the same room together"</i>
<b>Unattended Withdrawn Behaviour</b> <i>"So I would be concerned if they were sitting in their seat and it was obvious that nobody had come to engage with them for a very long period of time"</i>	<b>Issuing Orders to Residents</b> <i>"People being told to sit down, people being in their chairs the whole time frightened to actually stand up"</i>	<b>Lack of or Regimented Activity</b> <i>"Activities are regimented and not personalised, e.g. the half hour of bingo that no-one engages in"</i>
<b>Physical Appearance not Maintained</b> <i>"Resident's appearance isn't very well kept"</i>	<b>Individuality not Acknowledged</b> <i>"A younger person with dementia - had always worn his hair long and the care home staff tried to have his hair cut"</i>	<b>Lack of Available Aids to Support Independence</b> <i>"Lack of appropriate facilities to support eating and drinking"</i>
<b>Wariness Towards Staff</b> <i>"When a resident is sitting in the chair and staff are walking by, you can tell that some residents can be very wary of certain staff and someone that's been chatting quite freely will suddenly shut up when a certain member of staff comes by – you can see a change in that resident, you can sense that they are uneasy in that environment"</i>	<b>Staff Manipulation/Holding Power</b> <i>"There was a lot of manipulative behaviour between the staff and the smokers about when they could have them and when they were allowed to smoke"</i>	<b>Homeliness of Environment</b> <i>"Clinical feel no attempt at homeliness"</i>
<b>Physical appearance – Unkempt</b> <i>"Un-cleanliness. Lack of dignity, faeces in the nails"</i>	<b>Labelling/Objectifying</b> <i>"So the manager said she would tell me which residents I could speak to, we went down to the room and she said 'she can talk, she can talk, she can talk, she can't talk'"</i>	<b>Noise Levels</b> <i>"High level of noise, e.g. from television or radio"</i>

As you will see from the above tables, these factors are grouped around three main themes, PERSON, INTERACTION and ENVIRONMENT. Additionally an overarching concept of POWER is central to understanding the experience for the person with dementia, in relation to their power to influence their care experience and the way in which power is used to deliver care. These concepts form the focus for the observation using PIECE-dem. Your structured observations are focused upon observing the person in relation to:

- Their attempts to express their psycho-social, physical and spiritual needs;
- Their expression of their experience of the world;

- The interactions they initiate and experience from others, including considering the ‘act’ of the interaction, what it appears to be designed to achieve (intent) and the impact upon the person;
- The psycho-social, spiritual and physical environment surrounding the person and the extent to which this facilitates the meeting of their well-being.

Your observations should consider the use of power in all of the processes occurring during observation in relation to each person you observe. You need to remember that the focus of your observation is to capture the extent to which the care setting supports the person’s well-being and is therefore preventive, or contributes to a risk of experiencing abuse, neglect or loss of dignity.

### **Completing the raw data sheet**

The raw data sheet (fig 3) is shown at the end of this manual. The PIECE-dem coding focuses on three different engagement types accompanied by detailed notes in two separate sections. So in each 15-minute time frame you will be:

1. Recording interaction, engagement and disengagement during each minute of observation;
2. Making qualitative notes concerning the minute-by-minute experience for the resident of the world around them;
3. Making qualitative notes concerning the immediate psycho-social and physical environment surrounding the person.

Completion of the raw data sheet involves observing each resident for a total of 12 minutes in any 15-minute time frame. The additional three minutes are to ensure you have completed your observational notes, and to transfer to the other resident to be observed. However, these timeframes are for guidance only and there may be situations in which it takes longer to complete the observational notes, or to transfer to the next resident. In these circumstances, you should simply commence with your next participant as soon as you are able. Should a particularly important interaction or event occur when you are due to finish observing, you can carry on and record for a further 15 minutes, however this should be balanced with spending a similar amount of time with the other resident you are observing. See fig. 3b for an example of a completed raw data sheet.

## Recording engagement, disengagement and interaction

### Interaction

Interaction can be verbal e.g. spoken words or sounds, or non-verbal e.g. gestures, facial expression, eye contact. If you observe any interaction with another person (or an object that the person appears to be responding to as a person) during the time frame then you should record a tick in the 'Interaction' box for that minute. You should also jot down qualitative notes to describe what you saw that led to your coding of 'interaction'.

Interactions do not have to be considered 'positive' experiences in order to be coded as such. The determining feature of an interaction is its apparent intent on behalf of the resident and an element of response from another person (or object that the resident seems to be considering a person).

*Beth was sitting in her chair holding a doll she called Ruby. She held the doll tenderly and placed it on her lap. She spoke to Ruby, smiling and encouraging her while she changed her clothes. This was recorded as an interaction during the 4 minutes that it occurred.*

### Engagement

When coding engagement you are looking for signs of activity or responsiveness to others or the physical environment surrounding the person. Examples of engagement might include: walking, rubbing, touching, grooming, singing, eating, talking, calling, moaning, holding, looking, touching or manipulating an object. It can also include passive engagement such as watching what is going on, or attempts at interaction which achieve no response in return. Engagement does not have to be considered a 'positive' experience in order for it to be coded as such, it is the actions of the participant that determine whether engagement is recorded. If any engagement occurs during the time frame you should tick the 'Engaged' box and you should also jot down qualitative notes describing what you observed.

*Kath was sitting in the dining room, having just finished her pudding. She was looking around the room, and then looked down to her dish. She held her napkin and began to 'clean' the dish, rubbing and wiping the bowl and her spoon.*

## Disengagement

You should only record a person as disengaged if they are not engaged in any type of interaction, activity or other engagement during each one-minute time frame.

Disengagement can involve sitting with eyes closed but not appearing to be asleep, sitting with eyes open but not appearing to be focused on anything in particular, staring into the middle distance or sleeping. If the person is disengaged for the whole of the time frame then you tick the 'Disengaged' box. You should also jot down descriptive notes of what you observed that led to the coding of disengagement. Disengagement does not need to appear a negative experience for it to be coded as disengagement.

*John communicates solely with eye contact, gestures and occasional noises. A powerful episode of eye contact between a member of staff and John had just finished, John sighed and closed his eyes. His eyes remained closed for 3 minutes even though his breathing and his posture did not suggest that he was asleep.*

## Qualitative Notes for each 15 minute timeframe

Completion of the minute-by-minute notes section offer an opportunity to provide details to support the coding of engagement, disengagement and interaction, and to further enhance our understanding of the persons experience, through attempting to understand their expressions of need, feelings, actions, interactions with others or objects and their experience of their immediate environment. There is clearly potential for a large amount of qualitative data to be recorded at this point but observation timeframes should be dedicated predominately to observation of the individual. Qualitative notes should therefore aim to address the following:

### **Person**

Two major challenges are evident in observation with people who are highly vulnerable and experiencing significant levels of disability:

1. That levels of disability engendered by dementia and other co-morbid illness can make expression of need very challenging for the person and thus difficult to interpret for the observer;



2. You will not necessarily know the person with dementia, and thus you will not always be able to make an interpretation of what might be being expressed by them. While this may improve as observation of the person progresses, it is still challenging.

Thus the observer will need to consider overall whether the person's physical, psychological, social and spiritual needs are being met, reflecting upon the whole range of needs that might be evident to achieve well-being. Recording of possible expressions of need should be always be tentative and reflect upon the information received in your pre-observation summary and your growing understanding of the person. Thus you should record actions (and their possible intention) that may be observed/ expressed by the person with dementia. This includes their facial expression, body posture, bodily movements, attempts at communication, vocalisations. These expressions may include small gestures or movements, for example:

*Peter spends his day being cared for in a reclining chair. You have been observing him for nearly 2 hours, during which time he has remained in the same position. You notice that occasionally he lifts his bottom and legs up and down. Over the next 15 minutes this happens on a number of occasions. You note down that you wonder if he is uncomfortable and is trying to shift his position.*

### **Interaction**

Summarise the interactions occurring and consider which needs these interactions addressed. Key things to record include any direct action of another as it relates to the person with dementia. Therefore the nature of the interaction and how this appeared to be experienced by the person with dementia is recorded, as is the posture, tone, content, apparent intent, and use of touch occurring in the interaction. An act may not result in an obvious impact, however it should still be recorded. You will also make tentative comments on whether you felt interactions achieved a connection between the person with dementia and the other involved in the interaction.

### **Environment**

Finally, during your observations, you may also need to include relevant notes concerning the immediate physical and psycho-social environment surrounding the person with dementia. This will include considering things such as: whether pressure relieving aids are present for someone who spends a significant period of time in bed or lying in a chair, and if so, whether they are functioning; whether key objects are present in the environment that support that person's well-being. For example;

*Mrs Lewis appeared to be asleep in her chair for the whole of the 15 minute period of observation. She had a soft toy next to her, which she held onto while asleep. Her facial expression appeared to be calm and peaceful. Later in the observation you noticed she was asleep without her soft toy, her sleep appeared disturbed and her facial expression seemed distressed.*

### **Immediate environment**

Prior to and during each 15-minute observation, summarise the immediate physical and psycho-social environment surrounding the person with dementia in relation to their sensory experience, the management of the environment and the extent to which it appears to support the person's needs. This should include what the resident can hear, see, smell, and experience from where they are, as well as a consideration of how well it supports their physical, psycho-social and spiritual needs.

*Kate was sitting slouched in her chair next to a large television which was on. No-one in the room appeared to be watching it. Kate appeared to be asleep. A Cowboy film came on, with the first scenes being a gunfight, with lots of loud bangs and shouting. Kate awoke with a start, and a cry of alarm, she appeared distressed and frightened, and held her arms around herself rocking backwards and forwards. No-one appeared to notice her distress.*

In many instances, you may well find that consecutive observations of a participant requires the same information to be completed here, particularly if the environment does not alter a great deal or the resident does not move around the care setting frequently.

## **2 Hourly Summary of Observations**

As well as the brief notes recorded during the 15 minute timeframes, the PIECE-dem process is organised to allow summary notes to be completed for each participant at approximately 2-hourly intervals, (see fig.2). These breaks in observation are essential, not only to provide a rest from the rigours of observation (and the participants a rest from being observed!) but also to provide an opportunity to reflect upon the overall experience of the participant across the preceding period of observation. This is done through a process of considering your 15-minute observation data and discussion with your co-observer, which should result in the completion of summary notes (see fig.4 and fig 4b). Essentially, these two hourly summaries begin the process of analysing your data. This is begun at these intervals rather than at the end of the whole observation because it can be easy to forget the holistic impression of an environment and participant experience if you only return to the data several days later. Again there is clearly potential for a large amount of qualitative data to be included here and you will need to balance the time spent on this with the need to recommence 15-minute observations again. However, this part of the process is essential and as such you should ensure to facilitate it in practice.

The summary notes are structured so as to focus your particular towards the information that will help you to consider abuse, neglect and loss of dignity and the aspects of care that can lead to these experiences within a care environment or protect a person from them. The questions assist you to focus upon the experience for the person with dementia in relation to the following: their apparent expression of need and the extent to which their needs were met; their experience of interaction and whether a connection was made; the extent to which the environment around them supports their well-being; the exercise of power as it relates to the person with dementia, in particular whether the person was facilitated to take personal control to the extent they are able, or whether they are subjected to routines and activities over which they have no control.

In addition, the final sections of the summary sheet require you to reflect upon your experience of observation, the experience of staff and any other comments you may wish to make. The importance of reflection in this process cannot be understated. Not only is reflexivity a vital part of much qualitative research, but this step can be particularly important in poor care environments where you may witness distress which can be painful

and powerful. Without making time for this reflection and attempting to consciously articulate these experiences, it is possible that throughout the course of the observation you may end up normalising the experience of the residents and therefore downplaying the significance of your observations, or alternatively, viewing the whole experience as poor as a result of one apparently poor experience.

## Post-PIECE-dem: Analysis and Feedback

### Data Analysis: Making sense of the results of the tool

At the end of the analysis you will have two primary sources of data:

1. A set of 15-minute observation sheets containing a record of interaction, engagement and disengagement across 12 minutes, and short qualitative notes of their minute by minute experiences of the world.
2. A set of summary sheets for each participant which relate to particular blocks of observations and present an initial 'in the field' summary analysis of a person's experiences.

By reviewing these data sources for each participant, and referring back to the coding guidelines and theoretical framework of PIECE-dem you should be able to develop a tentative description of the care experiences of each participant, particularly with regard to protective or risk factors in relation to abuse, neglect or loss of dignity. In addition, by reviewing the data from across all four participants you should be able to produce a tentative description of the broader care experience across the care for people living with advanced dementia. These tentative conclusions can be used as the basis for your feedback to staff teams, or as the focus point for other aspects of a broader research project. However, it is important that you accept and embrace the tentative nature of your findings because:

- Whilst the tool is designed to maximise capture of a person's experience when they are unable to articulate it clearly themselves, the data produced still relies on the interpretation of another person. We can never definitively say what another person is experiencing, however rigorous or conclusive our data may seem. As such, we must be open and honest about the interpretations inherent in such an exercise.
- Observations have taken place across a specified and relatively short time frame. Whilst the tool is structured to attempt to capture a typical day of a participant, it may be that the day you have captured is, in fact, not typical in terms of the person's care experiences, the events in the care environment or the person's well being overall.

*Note regarding numerical descriptions:*

The recording of 'minutes spent' with regard to engagement, interaction and disengagement is **not** a quantitative measure. Instead, it is merely a way for you to identify, at a glance, the predominant experiences of the person. It is the qualitative notes of both data sources that allow contextualisation of the experiences, and as such the number of ticks or minutes spent should never be considered without their accompanying qualitative notes. This is because the descriptor 'interaction', 'engaged', or 'disengaged' does not, by itself, tell you about the impact of that experience on an individual's well-being and there should be no value judgements inherent in the use of the terms. Someone who is peacefully disengaged and showing no signs of discomfort may in fact be experiencing high levels of well-being. Conversely, a person who encounters an interaction that results in distress or anxiety may be experiencing ill-being.

**Feedback to the staff team**

For whatever purposes you have chosen to use PIECE-dem as a research tool, you should always incorporate a period of feedback to the care team in the home. This for a number of reasons:

- Your findings are tentative and as such, discussion with the staff team following a PIECE-dem can further contextualise this findings
- It can be stressful and onerous for a care home to participate in a research process, feedback is a way to ensure they receive something in return.
- It provides an opportunity for the staff team to feedback to researchers about their experience of the process, which can help to improve future research practice.
- By sharing information established during observation, (and being open to alternative interpretations of data) the power imbalance between the observer and the observed is mediated to a certain degree.
- A PIECE-dem is likely to have uncovered information that could improve upon the care experiences of residents, or maintain existing positive care experiences, and as such it is ethical practice to share this information. Whilst it is important to be mindful of potential negative consequences and difficulties in sharing this information, you should not start from the assumption that negative care

experiences observed during a PIECE-dem is indicative of individual or group behaviour that cannot be (or does not wish to be) improved.

There are a variety of different formats you may choose to use to feedback findings, and which one you choose will depend on the care home itself. Each care home and PIECE-dem experience will be different and your feedback should be tailored to the needs of that setting. However, the following guidelines should be observed:

1. Any feedback session should begin with an exploration of the perceptions of the staff concerning your work, how they experienced the observation and what they noticed about what was going on during the observation process.
2. Any feedback given should be explicitly tentative, particularly if you do not know the residents.
3. The method and content of your feedback should aim to 'do no harm' to the residents or staff of the home. This does not mean that you should not be honest in your feedback, but that you should remain mindful of the emotions it can provoke, the impact it may have once you have left and the realistic capacity for change of any organisation or individual and adjust your approach and content accordingly.
4. Begin with some general feedback concerning the experience of the residents and your perceptions of their experience of the world, if at all possible start with positives.
5. Use examples from your observations to illustrate care experiences as you describe them, although aim to maintain anonymity of participants where appropriate.
6. Summarise your observations of each of the four residents and their needs. Again, begin with the positives and move on to areas which may need addressing. Only use numerical data in the context of qualitative notes.
7. Structured feedback should be based on the questions asked in the summary sheets:
  - a. The person's apparent experience of the world including indicators of well-being and/or ill-being. This is particularly important for people who are unable to express their experience of the world verbally and should include your observations of their non-verbal expression;
  - b. Opportunities for the person to exert control/or be supported to take control;
  - c. The use of power in engaging with the person, through interactions and actions;
  - d. Your observations concerning the physical, spiritual and psycho-social needs and the extent to which these were met;
  - e. Interactions and connecting;

- f. Environment;
  - g. Staff experience of the person.
- 8. Give examples of the issues you are raising to highlight and create opportunities for discussion.
- 9. Agree an action plan for each of the residents/practice within the home at the end of the feedback session.



**Fig 2: Time Framework for Observation**

Day 1	1.00	15	30	45	2.00	15	30	45	3.00	15	30	45	4.00	15	30	45	5.00	15	30	45	6.00	15
Resident 1																						
Resident 2																						
Break																						
Day 1	30	45	7.00	15	30	45	8.00	15	30	45												
Resident 1																						
Resident 2																						
Break																						

Day 2	8 am	15	30	45	9 am	15	30	45	10 am	15	30	45	11 Am	15	30	45	12 pm	15	30	Summary and Prep for Feedback 12.45 to 2.00		
Resident 1																						
Resident 2																						
Break																						

**Fig 3: PIECE-dem Raw Data Sheet**

**Participant no.**

**Time Start:**

**Time Finish:**

Table 1	1	2	3	4	5	6	7	8	9	10	11	12	Total
Interaction													
Engaged													
Disengaged													
<b>Time Frame Notes</b>													
1													
2													
3													
4													
5													
6													
7													
8													
9													
10													
11													
12													
<b>Immediate Environment</b>													

**Fig 3b: Example of completed raw data sheet**

**PIECE dem Raw Data Sheet. Participant no. Ellen Time Start: 10.53 Time Finish: 11.08**

<b>Table 1</b>	1	2	3	4	5	6	7	8	9	10	11	12	Total
Interaction		x	x						x				3
Engaged													
Disengaged	x			x	x	x	x	x		x	x	x	9

<b>Time Frame Notes</b>	
1	Ellen continues to sit in the dining room, eyes open but staring into space
2	Carer moved her chair and asked Ellen to stand up, she didn't warn her that this was going to happen, Ellen appeared shocked. Carer took her arm and walked her towards the door, Ellen was walking at a pace that appeared faster than she could manage, and the carer was walking in front of her and didn't appear to notice til the last minute that Ellen was walking towards a door frame. Ellen appeared upset and alarmed. Carer sat Ellen down in a chair in the hallway.
3	
4	Ellen tried to get up; Carer moved her chair without telling her this was going to happen. She remained in the chair, looked down towards the floor after the action of the member of staff.
5	Ellen sitting in a chair, facial expression suggests she is distressed or sad, not engaged.
6	As 5
7	As 5
8	As 5
9	Carer interacts with Ellen and asks if she's ok, bends down to her eye level. Asks her what's wrong, Ellen doesn't respond to this, continues to look into space, staff moved away.
10	Sitting in a chair appears withdrawn, looking down towards the floor, eyes half closed, body posture appears quite tense, arms folded.
11	As 10
12	As 10

<b>Immediate Environment</b>
Still in the dining room, in a chair. Radio still on, on heart fm, next to her table. No evidence of social interaction, or engagement with other residents in the room. She is sat in a chair which is not supportive given that she appears sleepy. Has been in the dining room since before 8.30am. Hallway she moved into is dark and has little to offer stimulation; her soft toy is not by her chair as it was yesterday.

### Fig 4: Summary of Observation Block

Participant Number:

**Tick which observation block you are summarising**

Early afternoon	Late afternoon	Morning	Middle of day
Record number of minutes spent in each category			
Interaction		Engaged	Disengaged
Summarise your perception of the person's predominant experience of their world during this time period.			
To what extent was the resident able to exert control within their world and how was this achieved?			
How were the person's physical needs met?			
How were the person's psycho-social and spiritual needs met?			

**When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?**

--

**Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)**

\_\_\_\_\_

**What facilities were present within the environment to support the person's identity, occupation and inclusion? Were these facilities made use of in interactions with the person?**

--	--

**What emotions did you experience during this period of observation and why?**

\_\_\_\_\_

**How do you think the staff experience this person?**

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**Fig 4b: Example of a completed 2 hourly Summary**

**Summary of Observation Block**

**Participant Number: 05**

**Tick which observation block you are summarising**

Early afternoon	Late afternoon	Morning	Middle of day ✓
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<b>Record Number of minutes spent in each category</b>					
<b>Interaction</b>	<b>15</b>	<b>Engaged</b>	<b>24</b>	<b>Disengaged</b>	<b>11</b>
<b>Summarise your perception of the person's predominant experience of their world during this time period.</b>					
<p>John seemed at times to find it difficult to make sense of others intentions and the world around him. He sometimes appears concerned about what is happening, for example he sometimes frowns and pulls at his trousers when an interaction occurs. He sometimes says no to attempts at interaction or intervention, but is not angry with carers when they occur. So is this about his capacity to process information and understand?</p>					
<b>To what extent was the resident able to exert control within their world and how was this achieved?</b>					
<p>John seemed to have some capacity for taking control, but his difficulties with language seemed to be a source of frustration for him in this regard. He seems to exert control when interactions are attempted by carers, by saying no, or appearing to consciously ignore something someone is saying to him. He pushed his cup away from him when he had finished his tea, despite being prompted to continue to drink. Carers didn't always appear to accept no from him when they wanted to do something for him.</p>					
<b>How were the person's physical needs met?</b>					
<p>His physical needs for a safe transfer from chair to wheelchair seemed to be met appropriately; he did not appear concerned at all about this process. He was offered a number of drinks during the 45 minutes I was observing him. I did not see evidence of him appearing uncomfortable during the time I observed him and he was encouraged to walk a little way from the chair to the wheelchair.</p>					
<b>How were the person's psycho-social and spiritual needs met?</b>					
<p>Johns psycho-social needs in regard to relationships appeared to be met while I was there, as his wife came to visit and had lunch with him. He appeared to recognize her and was more alert and responsive when she arrived. However his need for enriching activities did not appear to be met, he spent a fair proportion of time appearing to seek interaction without receiving it, looking around and trying to engage eye contact with others with little success.</p>					
<b>When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?</b>					
<p>Interactions with Carers focused mainly on tasks to be completed. These were explained to him in some detail, but he often said no, which made me wonder if he understood what was being said to him. On one occasion, a carer made a considerable effort to talk with him and his wife, and he</p>					

smiled and laughed with her. Additionally he seemed much more animated with his wife, laughing and talking with her. However, there were occasions when carers talked over him, particularly when serving out dinner. He was not offered choice about what he wanted for dinner, and his wife indicated that he didn't like what he had been given. The carer was happy to change the meal offered at that point.

**Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)**

Interactions with carers seemed to rarely achieve a real connection with him. Where they were successful, the staff member had spent time bending down and attracting his attention for quite some time before explaining what he wanted to do. His wife did seem to make a connection with him, particularly when she showed him photographs of his grandchildren and she also took some time with him, patiently explaining what the event was that had happened.

**What facilities were present within the environment to support the person's identity, occupation and inclusion? Were these facilities made use of in interactions with the person?**

Little evidence of facilities that could support his identity and occupation needs. He did look at the newspaper at one stage, but seemed to struggle with this, I felt that this maybe too complex for him. While carers used his name, and talked with him, they didn't appear to know much about him. His wife showed him photographs and this seemed to be particularly enjoyable for him. She talked about family and he responded to this with gestures and nods and pointing at different people and their pet dog.

**What emotions did you experience during this period of observation and why?**

I felt quite frustrated because it seemed as though he could enjoy some activities and engagement but that he needed extra help with communication. He seemed to feel frustrated at times, (was I mirroring this?) wanting to engage and not being given the opportunity and I am concerned that there is a real risk of him becoming withdrawn if his attempts at communication aren't responded to.

**How do you think staff experience this person?**

It seems as though he came with a history of being challenging, from the home he was in previously and I wonder if carers find him a bit difficult to communicate with/ are worried about doing the wrong thing. Maybe they also are worried because they also know I am watching. A couple of the carers made a particular effort, one of the male carers interacted with him and his wife during dinner and seemed to make a connection, so seem to feel less concerned about interacting with him.

**Other comments**

How much is known about his life history and his occupation? Is there a way of involving his wife in working with him?

**Fig 5 : PIECE-dem Pre-Observation Summary Questions**

**Participant No:**

<p><b>Daily life:</b> What is this person able to do for themselves? What does this person need help and assistance with? What does this person enjoy doing? Who this person like spending time with? Does this person have spiritual beliefs that are known about?</p>
<p><b>Understanding the person's needs:</b> How do you know when this person is happy and content? How do you know when this person is unhappy or uncomfortable with what is happening to them? How do you know if this person is experiencing pain?</p>
<p><b>Health:</b> Does this person have a diagnosis of dementia? Do you know what type and when this was made? Does this person have any physical illnesses or problems that affect their daily life? What medication is this person taking currently?</p>
<p><b>Life before coming to the home:</b> What roles have been important to this person during their life? What influence do these roles and their history have on their behaviour now?</p>