Chapter 5  Getting started together: measuring and evaluating where we are now: Web resources

Contents of this resource

- Gathering evidence
- Example of a poster/flyer about gathering evidence
- Example of a poster/information sheet about carrying out observations
- Example of information sheet for families/decision makers of people for whom process consent might apply (e.g. people with severe cognitive impairment)
- Guide: Method and documentation of consent process for individuals with severely impaired capacity to consent to take part in a project
- Person-centred assessment tools
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- Method for facilitating a workshop on workplace culture
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Gathering evidence

Getting started together: Measuring and evaluating where we are now: web resources

Contents of this resource:

- a poster/flyer about gathering evidence;
- a poster/information sheet about observations of practice;
- an information sheet for families/decision-makers of people for whom process consent might apply (e.g. people with severe cognitive impairment);
- a guide to the method and documentation of the consent process for individuals with severely impaired capacity to consent to take part in a project (version 4, December 2009).
We’re off on our practice development journey to improve your care

Over the next few weeks, some of our team members, patients/residents, relatives and volunteers will be gathering evidence of what it is like to live and work in (insert name of workplace). They will be observing in (insert name of setting) and carrying out interviews. Information leaflets about this and our practice development are available from (insert where). The contact person is (insert name).
As part of our practice development work there will be some episodes or periods of observations taking place in (insert name of setting).

An observation is due to take place here on: between _________ and ___________

The observation is being carried out to take a more in-depth look at the way we organise and deliver care with patients/residents. The team are trying to understand more about the way they work and care for people so that they can improve what they do.

The observation will involve one or two members of the team sitting for a period of time observing and taking notes about what is going on around them. The notes will not mention anyone by name and will be used in the practice development work for learning and to help with developing action plans. There will be a feedback session for patients/residents and families at a later date.

If you are a patient/resident here . . .

You do not need to do anything different or special. If the observation involves any of your care you will be offered the opportunity to ask questions about what is happening and be asked whether you will give verbal consent for the observation to take place. Personal care will not be observed and your dignity and privacy will be respected.

Thank you for reading this information sheet
Example of information sheet for families/decision makers of people for whom process consent might apply (e.g. people with severe cognitive impairment)

We are inviting you to give your permission for __________________________ to be approached to take part in some evaluation of the care they receive.  
The aims of our work or project are:

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

The information that follows, in the form of questions and answers, tells you about the work or project. It is important that you understand what is in this information so that you can make an informed decision on behalf of your relative/friend. It says what will happen if your relative/friend chooses to take part and what the risks might be. Whether or not you do decide to give your permission for your relative/friend to be approached is entirely your decision.

This project is being carried out by a group from the team working in ([insert name of setting]).

At the end of this information sheet you will find a name and contact telephone number. Should you want to speak with anyone, this person can listen to you and answer any questions you may have. You will be contacted again in the near future to see whether you are willing to give your permission.

Thank you for taking the time to read this information.

For further information please contact:

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

The work or project is a practice development initiative to improve the way in which patients/residents in ([insert name of setting]) are cared for. We want to be able to include people with failing memory, cognitive impairments and disabilities caused through severe cognitive impairment, Parkinson’s and strokes as well as intellectual disabilities, so we can find out what their experiences are. Your relative/friend has been identified as someone who may have views and opinions that will be of interest to the project – no matter how limited their communication may seem to be.

Why has my relative/friend been identified as suitable to take part in this work/project?

Relatives/friends of all those people who are known to have poor memory, failing cognition from their disability and in particular from a severe cognitive impairment such as Alzheimer’s disease, are being asked to give permission for a member of the team to approach the patient/resident directly to see whether they would be willing to participate in some of the project. You are being asked to give your permission on the basis that you have known your relative/friend over a period of time. We are asking you to make a decision based on: what you feel your relative/friend would have wished for themselves or what you know about their last known wishes or instructions. Should you choose to give us permission to approach your relative/friend, we would use a specially developed and sensitive method for ensuring that your relative/friend is willing to participate. This method has been used in other similar work and research in this and other countries. Willingness to participate will be assessed by verbal communication, behaviour and facial expression and based on knowing from the team here how your relative/friend consents and indicates willingness or not on a day-to-day basis.

What would participation mean in practical terms – for me and for my relative/friend?

For you it would mean making a decision about giving your permission.  
For your relative/friend it means they would be first asked whether they would like to participate in the work or project. They would only be asked to participate in an activity or method that they can achieve and would find meaningful. This is most likely to be an informal and relaxed style of interview. Any interviews or conversations would be specially adapted to suit their remaining abilities.
Would taking part be of specific benefit to my relative/friend?

We anticipate that your relative/friend would enjoy having an opportunity to talk and to take part in this work. The encounter would bring opportunities for social conversations and some stimulation.

Are there any risks?

There is a possibility that your relative/friend may find it challenging to be asked about certain things. If so, we would stop on that occasion. Should your relative/friend find any aspect of the encounter distressing, on an ongoing basis, then we would not expect them to continue. Distressed behaviour would be taken as a sign of withdrawing their willingness and it would be respected. A member of the team who knows your relative/friend would be available to help ensure that their wishes are being understood and respected. Following any conversation or interview we would ensure that your relative/friend is left comfortable and a team member can monitor them to ensure there are no ill effects.

What if I give permission and my relative/friend declines to take part?

Your relative/friend would be asked for their ‘consent’ each time a member of the team meets with them. Any signs of declining or refusal expressed through words or behaviours would be respected.

How would confidentiality be protected?

Anything your relative/friend tells us would be kept anonymous. However, it is important that you understand that the findings from the work may be shared with professionals locally and in the organisation. There might also be presentations taking place at external events such as workshops and conferences.

What if I don’t want to give my permission or give it and later want to withdraw it?

You do not have to give your permission for your relative to be approached to participate. You are free to decide this now or to withdraw permission at any time. If you decide not to give permission or withdraw it later, you do not need to give any reason and this would not put at risk the care that your relative/friend is receiving.

Should you wish to contact a member of the work or project group here are the details:

Name: _______________________
Title: _______________________
Telephone numbers: _______________________
Email: _______________________

Jan Dewing, Brendan McCormack, and Angie Titchen.
© 2014 John Wiley & Sons, Ltd. Published 2014 by John Wiley & Sons, Ltd.
Guide: Method and documentation of consent process for individuals with severely impaired capacity to consent to take part in a project (version 4, December 2009)
(Dewing, 2009b)

Patient/resident name
Interviewer name

Part 1: Check list

1. Has permission to approach the patient/resident been obtained from carer/decision-maker or professional? YES/NO
2. Has the carer/decision-maker read the information sheet on consent and had the opportunity to ask questions? YES/NO
3. Have I discussed the patients/residents’ usual self-presentation and communication with carer and/or staff? YES/NO
4. Have I worked out the best way to introduce myself and the research to the patient/resident? YES/NO

Where the patient/resident has capacity please use an informed consent method (continue to Part 2). If not, please continue to Part 3.

Part 2: Assessing capacity to consent

Summary statement of remaining mental capacity

Guidance:
• Begin by assuming that the individual has the capacity to consent to take part, and look for evidence that may prove this in their day-to-day life and care.
• Make every effort to communicate with the person to explain what is happening.
• Make every effort to try to help the person make the decision or communicate choice using communication aids.
• See whether there is a way to explain or present information about the decision in a way that makes it easier to understand. If the person has a choice, ask whether they have information about the options.
• Find out whether the person understands what decision/choice they need to make and why they need to make it.
• See whether the person understands information about the decision and, if they can retain it, can they use it and weigh it to make the decision or choice.
• Where capacity fluctuates, see whether the decision can be delayed to allow time to help the person make the decision, or to give them time to regain the capacity to make the decision for themselves.

Part 3: Initial consent

Outline the approach to seeking consent from the patient/resident:
(Make notes on the location, time, information given, props or equipment used, questions and answers)
In what ways did the person indicate their consent?
(Identify verbal, non-verbal and behavioural signs. Do they match up with their usual way of indicating consent?)
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Who else was consulted (usually a family member involved in the patient/resident’s care and interested in their welfare)?
Name __________________________
Relationship to patient/resident __________________________
Consultee advice on whether the person who lacks capacity should take part in the project, and what they think the person’s feelings and wishes would be, if they had the capacity to decide whether to take part:
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Part 4: Ongoing consent monitoring

Date and time notes made: ________________
If you involve the patient/resident in more than one episode of conversation, you may need to treat each episode as a new interaction and make additional notes.
Was ongoing consent provided in a way that was consistent with the initial consent?
(If not then consent must be revisited in full. Any decision to continue must be justified)
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
At the end of the conversation/interview the person’s level of well-being was:
(Provide a description of behaviour, verbal and non-verbal signs and relative well-being level)
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
Has anyone independently tracked this person’s well-being during any of the consent process?
(If so, make a note of their observations in relation to the person’s level of well-being/ill-being)
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
Feedback given to carers/team was:
(Specify whether this was verbal or written)
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
State why you gave this feedback:
Your key responsibility is to ensure that anything that the patient/resident would wish to be kept confidential remains so.
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
Describe any interactions or interventions you made with the patient/resident in order to achieve a transition/return back into another social relationship or their environment of care:

__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Signature: _______________________

Issues to raise in the practice development group/project:

__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
Person-centred assessment tools

The next two person-centred assessment tools are filled in by the care team. Their distribution, collection and analysis would be organised by the practice development coordinating group or evaluation sub-group.

The aim of using this next questionnaire is to measure the extent to which the care in your workplace is experienced by care teams as being person-centred. The questionnaire consists of 13 statements about the care. You are asked to decide to what extent you think the statements correspond to your own experiences of working in your setting. You are asked to put a cross in the box for the alternative that you think best describes your experience. It is important that you answer all the statements, so if you feel uncertain, pick the alternative closest to your experience.

The Tool for Understanding Residents’ Needs as Individual Persons
(Edvardsson et al., 2010)

THIS TOOL MUST NOT BE ADAPTED IN ANY WAY

The development of this tool has been supported by the Australian Government, La Trobe University, the J.O and J.R. Wicking Trust – Medical and Scientific Research Grants (ANZ Trustees), and Umeå University.

Instructions for use:
This tool provides the basis for enhancing person-centredness of facilities providing care for people with dementia.
The package contains 39 statements about five domains central to person-centred care; the care environment, staff attitudes towards people with dementia, staff knowledge of dementia, the organisation of care, and the constituents of care provided. The individuals targeted for this educational package are firstly asked to decide to what extent they feel the statements correspond to their experiences of the facility, and to put a cross in the box for the alternative that comes closest to their experience. Secondly, each dimension and item in the package is to be used for reflective group discussions about the current facility, with an aim to identify areas for improvement.

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### The care environment

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
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<th>5</th>
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</thead>
<tbody>
<tr>
<td>1. The environment supports residents to express their personal identity.</td>
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<td>2. The environment feels chaotic.</td>
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<td>3. There is a homely feel to the place.</td>
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<td>4. The environment supports personal choice.</td>
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<td>5. It is hard for residents in this facility to find their way around.</td>
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<td>6. There is a pleasant atmosphere.</td>
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<tr>
<td>7. Residents are able to access outside space as they wish.</td>
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<td>8. I would like to live here if I had dementia.</td>
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<td>9. Social participation is important for people with dementia.</td>
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<td>10. People with dementia have hopes.</td>
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<td>11. People with dementia can have meaningful relationships.</td>
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<tr>
<td>12. It is important to know the life history of people with dementia.</td>
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<tr>
<td>13. People with dementia have ways of communicating what they want and don't want.</td>
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<tr>
<td>14. In dementia the body remains but the person is gone.</td>
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<tr>
<td>15. People with dementia should be allowed to form sexual relationships.</td>
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<tr>
<td>16. The quality of the interaction between staff and residents is more important than getting the tasks done.</td>
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<td>17. Dementia reduces the experience of pain.</td>
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<td>18. Challenging behaviours are inevitable with dementia.</td>
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<td>19. People with dementia should always be oriented to reality.</td>
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<tr>
<td>20. People with dementia are as different from each other as any other groups of people who share a disease category.</td>
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<tr>
<td>21. There is often no alternative to using restraint.</td>
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</tr>
<tr>
<td>The care environment</td>
<td>Disagree completely</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Agree completely</td>
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<tr>
<td>22. We often discuss how to give person-centred care.</td>
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<td>□</td>
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<tr>
<td>23. It is necessary to hurry residents to accomplish all that has to be done.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>24. We have to get the work done before we can worry about a homelike environment.</td>
<td>□</td>
<td>□</td>
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<td>25. This organisation prevents me from providing person-centred care.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>26. We often evaluate whether or not the care provided is person-centred.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>27. Labels (e.g. wanderer and screamer) are used here to describe individuals.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>28. We are free to alter work routines based on residents' preferences.</td>
<td>□</td>
<td>□</td>
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<td>29. I simply do not have the time to provide person-centred care.</td>
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<td>□</td>
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<td>30. I feel supported by the organisation I work in.</td>
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<tr>
<td>31. Residents are involved in care decisions when they can.</td>
<td>□</td>
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<tr>
<td>32. We have formal team meetings to discuss residents’ care.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>33. In my workplace residents are given opportunities to perform tasks according to their abilities.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>34. The life history of the residents is formally used in the care plans we use.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>35. Assessment of residents’ needs is undertaken on a daily basis.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>36. Residents can wake up and start the day when they prefer.</td>
<td>□</td>
<td>□</td>
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<tr>
<td>37. Residents have a variety of foods to choose from.</td>
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<tr>
<td>38. Residents are offered the opportunity to be involved in individualised everyday activities.</td>
<td>□</td>
<td>□</td>
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<td>39. Residents can choose between interacting with others and being alone.</td>
<td>□</td>
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</tbody>
</table>
The Person-centred Care Assessment Tool (P-CAT) (Edvardsson et al., 2010)

THIS TOOL MUST NOT BE ADAPTED IN ANY WAY

Instructions for use:
This questionnaire aims to measure the extent to which the care within a facility is experienced by staff as being person-centred. The questionnaire consists of 13 statements about the care. You are asked to decide to what extent you think the statements correspond to your own experiences working in your current facility. Please put a cross in the box for the alternative that you think best describes your experience. It is important that you answer all the statements, so if you feel uncertain, pick the alternative closest to your experience.

The development of this tool has been supported by the Australian Government, La Trobe University, the J.O and J.R. Wicking Trust – Medical and Scientific Research Grants (ANZ Trustees), and Umeå University.

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<table>
<thead>
<tr>
<th>The content of care</th>
<th>Disagree completely</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Agree completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. We often discuss how to give person-centred care.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>3. The life history of the residents is formally used in the care plans we use.</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>□</td>
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<tr>
<td>4. The quality of interaction between staff and residents is more important than getting the tasks done.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>5. We are free to alter work routines based on residents’ preferences.</td>
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<td>6. Residents are offered the opportunity to be involved in individualised everyday activities.</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>□</td>
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<tr>
<td>7. I simply do not have the time to provide person-centred care.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>8. The environment feels chaotic.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. We have to get the work done before we can worry about a home-like environment.</td>
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<td>□</td>
<td>□</td>
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<td>□</td>
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<tr>
<td>10. This organisation prevents me from providing person-centred care.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>11. Assessment of residents’ needs is undertaken on a daily basis.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>12. It is hard for residents in this facility to find their way around.</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>13. Residents are able to access outside space as they wish.</td>
<td>□</td>
<td>□</td>
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</table>
The purpose of this workshop is threefold:

1. Collect evidence of the experience of the current culture.
2. Develop a shared vision of the current workplace culture and the attributes of this culture and to compare it with what an effective, person-centred workplace culture that has practice development needs to look like. Such a culture would be a transformational culture.
3. Learn about the attributes or features of an effective workplace culture.

This method can be facilitated with a small group (8–10) or a very large group of stakeholders (which could go up to 50 people) divided into smaller groups. If you want to work with a very large group, then it is recommended that the workshop is facilitated by an experienced practice development facilitator.

The groups are asked to create a collage to reflect the current workplace culture(s) in the workplace (note, there is likely to be more than one culture operating in the workplace, in the different staff groups for example). The creative process enables understanding of the workplace culture(s) to emerge in a commonsense way based on actual experience.

Fig. 5.2 Example of a collage using a variety of materials
They will then make changes to the current culture to visualise or enact what an effective workplace culture would look like.

You will need:

- approximately 1 hour for a small group and 2 hours for large numbers of participants;
- materials, which could include felt-tip pens, paints, crayons, pastels (plus any other drawing materials you want to include); magazines and newspapers or a supply of images; clay, scissors, glue sticks; newspaper or other floor covering if paint is being used; everyday small leftover and ‘junk’ items (e.g. wine bottle tops/corks, plastic containers, balloons), leaves, flowers, small twigs and branches, silver-coloured foil, coloured paper, tissue paper and card, felt – these are just a few ideas to get you started;
- a large room with chairs around the side;
- the handout on an effective workplace culture (see Chapter 5) with copies for all participants;
- a flipchart easel, paper and marker pens;
- one or two facilitators (usually two facilitators for 20–25+ participants);
- a camera to take pictures of the collages.

Key activities

Introductions and purpose. (5 mins)

Creative work in small groups (between 4–8) to produce the collage of the current workplace culture. (30 mins)

Gallery viewing and sharing of collages. Facilitator to take photos of the collages during the gallery viewing. At this point, it is important that you enable sharing to take place without the viewers making comments about the quality of work or ‘imposing’ their own or ‘telling’ the creator how things are done in that workplace. You can invite comments on:

- What I see in this collage is ………
- What I feel from this collage is ………
- What I ask myself about this workplace is ……………

Then invite the groups to do further creative work to make changes on the collage to reflect on the culture they would really like in the workplace. Ask the groups to decide on the three most crucial changes that need to be made and to write them on flipchart paper.

Go round each of the groups to review the changes they have made and the consequences as they experience them. Take photographs of the changed collages. (30 mins)

Introduce the handout at this point and ask them whether they can see evidence of the attributes (features) of an effective workplace culture in their changed collage. (30 mins)

Reflective discussion in the small groups, which could be based on these or similar key questions: (20–25 mins).

- What are the attributes (features) of an effective workplace culture?
- In terms of action planning for an effective workplace culture, what would your three priorities be?
- What are the consequences for patients/residents and the team of the current and aspirational workplace cultures?
- How can transformation from the current to future workplace culture be facilitated?
- What will you do to contribute to this happening?

Responses to the questions should be written on the flipchart sheet.

The photographs, the flipcharts with the three most crucial changes to make, and the responses to the handout and the questions are all evidence that can be used to help develop the practice development plan.

Even if time is short our experience of facilitating the workshop with large numbers of people over the last decade or more is that it is a really good investment of time in terms of the impact it has on people and the subsequent changes they make.
Useful websites and resources

For ease of use, this section is also available on the companion website: www.wiley.com/go/practicedevelopment/workbook

The Productive Series

www.institute.nhs.uk/quality_and_value/productivity_series/the_productive_series.html


The following link takes you to a description about a Patient-Centred Care Project that drew on an approach called experience-based co-design (EBCD). This project aimed to improve the experience and quality of care for patients receiving treatment for breast cancer and lung cancer (www.kingsfund.org.uk/current_projects/point_of_care/ebcd_evaluation.html).

With the right support, people living with dementia can express opinions about services. This report of a study explored how staff can encourage people with dementia to express their views and preferences in the course of day-to-day practice. Allan (2001) (www.jrf.org.uk/bookshop/eBooks/186134810X.pdf; www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services).

Talking Mats might be an idea you would like to consider (www.talkingmats.com). A project found that Talking Mats can be used by many people with dementia and that it improves their ability to communicate. The report suggests that Talking Mats can provide family and staff with a tool to enable many people with dementia to communicate their needs and preferences more easily than through usual conversation (www.jrf.org.uk/publications/using-talking-mats-help-people-with-dementia-communicate).

Augmentative and Alternative Communication (AAC) covers a wide range of techniques to support or replace spoken communication. This website offers examples of low and high-tech methods, including gesture, signing, symbols, word boards, communication boards and books, as well as Voice Output Communication Aids (VOCAs) (www.communicationmatters.org.uk/page/talking-mats).

The Online Evaluation Resource Library (OERL) for education. This library was developed for professionals seeking to design, conduct, document or review project evaluations (http://oerl.sri.com/te.html).

OTseeker is a database that contains abstracts of systematic reviews and randomised controlled trials relevant to occupational therapy. Trials have been critically appraised and rated to assist you to evaluate their validity and interpretability. These ratings will help you to judge the quality and usefulness of trials for informing clinical interventions (www.otseeker.com).