Incorporating an advance care planning screening tool into routine health assessments with older people

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Abstract
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Incorporating an advance care planning screening tool into routine health assessments with older people

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Abstract. General practice is arguably the ideal setting to initiate advance care planning (ACP), but there are many barriers. This pilot study was designed to assess the feasibility, acceptability and perceived utility of a nurse-facilitated screening interview to initiate ACP with older patients in general practice. Patients were recruited from four general practices in Sydney, Australia. General practice nurses administered the ACP screening interview during routine health assessments. Patients and nurses completed a follow-up questionnaire consisting of questions with Likert responses, as well as open-ended questions. Descriptive statistics and content analysis were used to analyse the data. Twenty-four patients participated; 17 completed the follow-up questionnaire. All patients found the ACP screening interview useful and most felt it would encourage them to discuss their wishes further with their family and general practitioner. Several patients were prompted to consider legally appointing their preferred substitute decision-maker. All six participating nurses found the screening interview tool useful for initiating discussions about ACP and substitute decision-making. This nurse facilitated screening tool provides a simple, acceptable and feasible approach to introducing ACP to older general practice patients during routine health assessments.

Additional keywords: aged, general practice, health assessment, primary health care, screening tool.

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Introduction

The Royal Australian College of General Practitioners defines advance care planning (ACP) as a ‘process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves’ (Royal Australian College of General Practitioners (RACGP) 2012). The value of ACP is widely recognised (Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers’ Advisory Council 2011). ACP allows patients the opportunity to plan and prepare for their future care, choose an appropriate substitute decision-maker, and inform their family and healthcare providers about their wishes.

Clinical trials have examined the effect of ACP on patient and family outcomes in in-patient (Abel et al. 2013), residential aged care (Silvester et al. 2013) and palliative care (Blackford and Street 2012) settings. Demonstrated benefits of ACP include reduced number of days spent in the acute care system and intensive care unit in the last year of life, being more likely to die in the person’s place of choice and improved outcomes for the person’s bereaved relatives (Detering et al. 2010; Blackford and Street 2012; Abel et al. 2013; Silvester et al. 2013; Brinkman-Stoppelenburg et al. 2014; Houben et al. 2014).

It is helpful to have discussions regarding ACP at a time of medical stability, in a non-threatening environment with a health professional that the patient has a good relationship built up over time. Therefore, general practices are ideally positioned to take a key role in initiating ACP discussions (Tierney et al. 2001; Cartwright and Parker 2004). However, it is acknowledged that clinicians face several barriers to ACP, including lack of experience in ACP, time pressures and the fear of causing distress to patient, family and the treating health professional (Bergman-Evans et al. 2008; Rhee et al. 2012; De Vleminck et al. 2014; Lund et al. 2015).
What is known about the topic?

- Advance care planning (ACP) can improve end-of-life care for patients and families. General practice has been advocated as an ideal setting to initiate ACP, however, there are many barriers.

What does this paper add?

- This study piloted a simple tool to enable general practice nurses to initiate ACP conversations during routine health assessments with older patients. The tool was feasible and acceptable for patients and nurses.

One promising approach to overcoming the fear of causing distress to patients, family and the treating health professional is the use of a screening interview tool to normalise the topic of ACP and introduce it to patients in a non-threatening manner. The administration of the tool by other health professionals (such as a nurse) may also help address the barrier caused by the time pressures faced by the doctors. Cheang et al. 2014 piloted a simple ACP screening interview tool with older inpatients in a tertiary hospital to introduce the topic of ACP, determine the patient’s preferred substitute decision-maker, ascertain any ACP previously completed by the patient and assess the patient’s willingness to further discuss ACP. The screening interview tool was found to be highly acceptable and feasible to administer.

Introducing ACP in primary care may require a differing approach to the acute care setting (Hinders 2012; Schonfeld et al. 2012; Boddy et al. 2013). We have therefore adapted the ACP screening interview to be suitable for administration by general practice nurses (GPNs) to medically stable patients in primary care settings. In this paper, we report on the findings of a pilot study conducted with the aims of assessing the acceptability, feasibility and perceived utility of a GPN-administered ACP screening interview tool as part of a routine annual elderly health check in general practice. The study also aimed to collect suggestions for change and improvement from the patients and the GPNs.

Methods

An ACP screening interview tool developed previously for older hospital inpatients (Cheang et al. 2014) was adapted by the authors (two GPs and one palliative care physician) for administration by GPNs to medically stable patients in the general practice setting (Appendix 1). It contains a structured list of questions and prompts for health professionals to ask patients and record their responses. The tool introduces the topic of ACP, determines the patient’s preferred substitute decision-maker; identifies previous instances of ACP discussions or documents previously completed by the patient; and assesses the patient’s willingness to further discuss ACP.

Four general practices in metropolitan Sydney agreed to participate in the study. The screening interview tool was administered by GPNs during the routine ≥75 years health assessment (shortened in this paper to 75+ years health assessment) of eligible patients. This is a Medicare-funded annual comprehensive assessment of patients aged ≥75 years conducted in general practices, often involving initial GPN assessment followed by a GP review. Each participating practice, including the GPN(s), received 1 h of group training by the researcher. This covered the background to the research, how to use the screening interview tool, definitions of ACP and person responsible (Appendix 1), techniques for introducing the concepts of enduring guardianship and ACP, as well as how to manage any patient distress.

Participant recruitment

Over a 10-month period in 2015–16, six GPNs working in four general practices were invited to approach all eligible patients having a 75+ years health assessment to assess their willingness to be involved in the research. Participating general practices were invited to recruit up to 10 patients from each practice. No funding or research assistant support was available to assist general practices with recruitment.

Eligibility criterion was attending the practice for a 75+ years health assessment. Exclusion criteria were inability to understand the study information, inability to provide informed consent, or cognitive dysfunction (either known previously or identified as part of the 75+ years health assessment).

Data collection

After providing written informed consent, participating patients were asked the ACP screening interview tool questions by the GPN, during the 75+ years health assessment. Patient responses were recorded in the patient record. A de-identified copy of the results was provided to the study investigators. After completing the health check, the patient was invited to complete a demographic and feedback questionnaire. The latter was composed of 11 questions where the patient was asked to rate their level of agreement (from Strongly agree to Strongly disagree) with statements about their experience of the screening interview. In addition, patients were asked if they would have preferred to discuss these topics at a different time; with a different healthcare practitioner; if any questions should be modified, removed or added to the screening tool; if the patient was aware these topics could be discussed with the GPN or GP; if the patient had previously completed a will or appointed an enduring power of attorney (substitute decision-maker for financial matters in NSW); and if there were any other comments the patient felt were relevant.

At the completion of the project, the participating GPNs completed a similar feedback questionnaire about the ACP screening interview tool, including questions about any changes they would suggest; its usefulness for initiating ACP discussions; whether they would use it in the future; and if they would recommend it to other GPNs.

Data analysis

Descriptive statistics were used to analyse patient characteristics and their responses to questions consisting of Likert scale responses. The written comments of GPNs were analysed using qualitative content analysis.

Ethics

Ethics approval was granted for this study by the RACGP National Research and Evaluation Ethics Committee (NREEC; reference NREEC 14–015).
Results

Screening interview tool completion and demographics

A total of 24 patients participated in the study and completed the GPN-facilitated ACP screening interview. It is not known how many participants were approached to participate in the study or the reasons for declining. Two practices recruited 10 patients each, one practice recruited three patients and the other one patient.

Seventeen patients completed at least part of the feedback and demographics questionnaire, with 15 patients completing the demographic questions. The mean age of participating patients was 81.4 years (range 75–90 years). Table 1 presents the other demographic data of the responding patients. Demographic data are not available for the other nine patients who participated in the study.

Table 2 summarises participants’ responses to the screening tool questions. Two patients volunteered specific wishes regarding their end-of-life care. One stated they would not want attempts at resuscitation and another stated that ‘I would not want to be kept alive if I had no quality of life’.

A single patient had their person responsible present with them during the meeting with the nurse.

The screening questions took less than 5 min to complete for 13 patients, up to 10 min for three patients, 11–15 min for four patients and 30 min for one patient.

Patient feedback questionnaire

The Likert questions in the patient feedback questionnaire were completed by 17 of the 24 participating patients, with results summarised in Table 3.

Fifteen patients of the 24 participating patients responded to the other items in the patient feedback questionnaire. All 15 patients had previously completed a will and 13 had a valid enduring power of attorney. No patients thought any questions needed to be rephrased or removed from the screening tool. Seven of the 15 patients were unaware that the topics in the screening tool could be discussed with a GPN or with their GP. All patients felt the GPN was the appropriate healthcare professional to discuss these topics. One patient would have preferred to discuss the topics at home.

One patient noted ‘I think it (the screening tool) is an excellent idea and that a regular prompt or reminder from the practice would be good’.

Nurse feedback questionnaire

This was completed by all six GPNs who participated in the study. All of the GPNs agreed, five of them strongly, that the screening tool had been useful in initiating discussion with patients regarding ACP and that the questions were appropriate.

The nurses all agreed that no questions should be removed or rephrased and no other questions needed to be included. One nurse said ‘it gave a platform to discuss end of life care and wishes’ [PN1].

Four nurses felt they would use the screening interview tool again, one was uncertain and another reported the tool needed some further introductory comments before she would be happy to use it [PN5]. Five of the six nurses indicated they would recommend the screening interview tool to other GPNs. Five nurses felt the 75+ years health assessment was the best time to use the screening interview tool, while the remaining nurse was uncertain noting, ‘I think that we should give them information about ACP and invite back to discuss further as health check is already quite involved’ [PN6]. One GPN commented they had ‘already incorporated (these questions) into over 75 health assessment’ [PN2].

Other comments made by the GPNs included the benefits of making patients aware of ACP through having posters in the waiting room and pamphlets about ACP easily available.

Discussion

In this study, the nurse-administered ACP screening interview tool was found to be acceptable to patients and nurses and feasible to implement during routine health assessments with older patients in general practices. Nearly all patients found the screening tool to be helpful and felt the health assessment was an appropriate time to discuss this topic. All patients reported feeling comfortable answering the questions; that the nurse was the appropriate healthcare professional to discuss this with; and that their feelings were appropriately managed. None of the 17 patients said the questions made them feel uncomfortable. This is reassuring as health professionals are often concerned about creating patient discomfort and anxiety when broaching the subject of ACP (Rhee et al. 2013).

The results therefore suggest that the 75+ years health assessment is a suitable and practical time to ask routine screening questions about ACP. Lund et al. (2015) have
documented the need for simple tools to increase the chance of ACP being incorporated into routine care. This screening interview tool could be effective in this regard and could lead to further, more in depth, discussion about ACP in interested and willing patients.

The ACP screening interviews revealed several areas where the practice was not aware of patients’ preferences. Half of patients had completed a document appointing a formal legal guardian for substitute medical decisions (enduring guardian in New South Wales), but this was noted in the practice records only on one-third of occasions. Four out of 24 patients wanted a person different from their routinely recognised ‘person responsible’ (according to the hierarchy for substitute medical decisions in New South Wales) to make medical decisions for them.

### Table 2. Patients’ responses to the nurse-facilitated Advance Care Planning Screening Interview tool (n = 24 unless otherwise stated)

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who the patient would want to make medical decisions for them in an emergency if they were to be unwell to speak for themselves</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>41</td>
</tr>
<tr>
<td>Relative</td>
<td>46</td>
</tr>
<tr>
<td>Friend/other</td>
<td>13</td>
</tr>
<tr>
<td>(Nurse question) Is this person the ‘person responsible’ according to the Guardianship Act?</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>83</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
</tr>
<tr>
<td>Patient answered yes to ‘Have you ever appointed a formal Enduring Guardian?’</td>
<td>50</td>
</tr>
<tr>
<td>A copy of the enduring guardianship is available in the patient record</td>
<td>33(^A)</td>
</tr>
<tr>
<td>Enduring Guardian contact details available in patient record</td>
<td>75(^A)</td>
</tr>
<tr>
<td>Patient answered yes to ‘have you talked to your family about your wishes, values and beliefs about your medical treatment and care in case you become seriously unwell?’</td>
<td>63</td>
</tr>
<tr>
<td>Patient answered yes to ‘have you talked to a doctor about your wishes, values and beliefs about your medical treatment and care in case you become seriously unwell?’</td>
<td>29</td>
</tr>
<tr>
<td>Patient answered yes to ‘have you ever had your wishes regarding the medical care in the case that you became seriously ill, formally documented in an advance care plan or directive?’</td>
<td>29(^B)</td>
</tr>
<tr>
<td>A copy of the ACP already in the practice patient record</td>
<td></td>
</tr>
<tr>
<td>Patient answered yes to ‘Have you heard of advance care planning or advance care directives?’</td>
<td>50</td>
</tr>
<tr>
<td>Patient answered yes to ‘would you like an information brochure about ACP?’</td>
<td>80</td>
</tr>
<tr>
<td>Patient answered yes to ‘would you be comfortable if a member of the practice were to further discuss advance care planning with you?’</td>
<td>100</td>
</tr>
</tbody>
</table>

Regarding this discussion the patient was:

- Very comfortable | 88 | 21 |
- Somewhat comfortable | 12 | 3 |
- Uncomfortable | 0 | 0 |

\(^A\)Of the 12 patients with a previously appointed Enduring Guardian.

\(^B\)Of the seven patients with a completed ACP.

\(^C\)Of the 20 patients who responded to these questions.

\(^D\)Of the 17 patients who had not previously completed an ACP.

### Table 3. Patients’ responses to the feedback survey (n = 17)

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Not sure</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found the advance care planning (ACP) discussion helpful</td>
<td>11 (65)</td>
<td>5 (29)</td>
<td>1 (6)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>There were questions in the ACP screening interview that made me anxious</td>
<td>2 (12)</td>
<td>1 (6)</td>
<td>2 (12)</td>
<td>4 (24)</td>
<td>8 (47)</td>
</tr>
<tr>
<td>This was an appropriate time to discuss these issues</td>
<td>11 (65)</td>
<td>5 (29)</td>
<td>1 (6)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>I felt comfortable answering the questions the nurse asked me about ACP</td>
<td>12 (71)</td>
<td>5 (29)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>I would like further conversations about ACP with the nurse</td>
<td>1 (6)</td>
<td>7 (41)</td>
<td>3 (18)</td>
<td>4 (24)</td>
<td>2 (12)</td>
</tr>
<tr>
<td>I would like further conversations about ACP with my GP</td>
<td>4 (24)</td>
<td>9 (53)</td>
<td>2 (12)</td>
<td>0 (0)</td>
<td>2 (12)</td>
</tr>
<tr>
<td>I would recommend this discussion with the nurse to other patients</td>
<td>13 (76)</td>
<td>2 (12)</td>
<td>2 (12)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>I felt the nurse handled the discussion in an appropriate and sensitive manner</td>
<td>14 (82)</td>
<td>3 (18)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>I believe as a result of this discussion with the nurse, I am more likely to talk with my GP about my wishes for care if I were to become seriously unwell in the future</td>
<td>9 (53)</td>
<td>7 (41)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (6)</td>
</tr>
<tr>
<td>I believe as a result of this discussion with the nurse, I am more likely to talk with my family about my wishes for care if I were to become seriously unwell in the future</td>
<td>8 (47)</td>
<td>8 (47)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (6)</td>
</tr>
<tr>
<td>My feelings were dealt with adequately during the discussion with the nurse about ACP</td>
<td>13 (76)</td>
<td>4 (24)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
(Guardianship Act of 1987, NSW, Sect 33A, http://www.lawislation.nsw.gov.au/inforce/580b32d3-f8fd-4a1f-dc87-c6d1f165a95b/1987-257.pdf, accessed June 2016). An instructional advance care directive or advance care plan had been completed by nearly one-third of patients; however, only two were available in the practice record. While two-thirds of patients had spoken with their family regarding their wishes for future care, less than one-third had spoken with their doctor. These findings highlight the important role that the ACP screening interview tool can play in helping practices to identify and record the patients’ preferences and ACP documents. This information is vital in ensuring that healthcare decisions, especially in a medical emergency, reflect the preferences of the patient.

The findings show that the ACP screening interview tool could help GPs and GPNs in initiating ACP discussion with the patient and their family. In our study, all patients who had not previously discussed ACP said they would be comfortable to have further discussions with the practice about ACP. After completing the screening interview tool, nearly all patients reported being more likely to discuss their wishes for their future care with both their family and their GP. Feedback from the participating GPNs was similarly positive and suggested that having a simple, easy-to-follow list of questions like those in the screening interview, could make approaching these discussions less intimidating to staff. Therefore, the ACP screening interview tool could help address an important barrier faced by GPs in ACP, which is the fear of causing distress to patients (De Vleminck et al. 2014).

Incorporating the ACP screening interview tool as part of the 75+ years health assessment may make it more likely that elderly patients’ readiness to discuss ACP is routinely explored and help address two important barriers faced by GPs in terms of ACP: time pressure and lack of remuneration (Rhee et al. 2012). The nurse participants recommended incorporating the questions into the electronic general practice template for the 75+ years health assessment, including the introductory statements given in Appendix 1.

Strengths and limitations

This pilot study provided important information on the acceptability and feasibility of the ACP screening interview tool in general practice settings, thus allowing the further refinement of the tool. A strength of the study, which increases its generalisability, is the trialling of the screening interview in typical general practices, rather than practices with a special interest in palliative care.

There are several limitations with this study. The patient group was small, and all were from metropolitan Sydney. Nearly half the patients had completed tertiary education and resided in a higher socioeconomic area; it is possible that the numbers having completed enduring guardianship and ACP could be higher than in the general population. Only patients who were able to read and write English were recruited. Therefore, the findings may not be generalisable to rural populations, people from culturally and linguistically diverse (CALD) backgrounds and people with lower level of education and socioeconomic status.

In the future, it would be useful to repeat the study in a rural population and in a lower socioeconomic area to see if the ACP screening interview tool is acceptable and feasible in these settings. In addition, a large-scale study could be conducted to evaluate the ACP screening interview tool’s effectiveness in encouraging the initiation of ACP and assisting the health professionals to become more aware of completed ACP documents.

Conclusion

The GPN administration of the ACP screening interview tool during routine elderly health assessments may provide a non-threatening method for promoting awareness about ACP and assessing patients’ readiness to engage in ACP discussions.

Implications for practice

ACP is important to ensure patient wishes are respected in the event of serious medical illness. The ACP screening interview tool could provide a simple, non-threatening approach, acceptable to both staff and patients, to introduce discussions about ACP as part of routine elderly health assessments in primary care.

Since completing this study, the ACP screening interview tool has been further refined to be relevant to all Australian states and territories, and incorporated into a national toolkit and multicomponent training program for primary care clinicians called the Advance Project (The Advance Project 2018). The refined tool is freely available from www.theadvanceproject.com.au in electronic formats that can be incorporated into practice software. Online training and demonstration videos explain how to use the tool.

Conflicts of interest

The authors declare no conflicts of interest.

Acknowledgements

The authors acknowledge the four General Practices involved with the research project: Cremorne Medical Practice, Cremorne GP, Seaford Medical Centre and Lynwood Medical. We are very grateful for all of the practice members’ support, particularly the General Practice Nurses who participated. This research did not receive any specific funding.

References


Appendix 1. Advance Care Planning Screening Interview tool

1. Who would you like to make decisions for you in an emergency if you were too unwell to speak for yourself?

Prompts for the practice nurse:
- Is this the person responsible according to the Guardianship Act 1987 (see below)? If not, suggest that they consider appointing an enduring guardian.
- If yes, record this person’s contact details in the medical record?
- Is this person the same as next of kin?

2. Have you appointed an Enduring Guardian who could make medical decisions on your behalf (please note this is different to a power of attorney for financial decisions)?

Prompts for the practice nurse:
- If so is a copy in the patient record?
- Are the Enduring Guardian contact details in the patient record?

3. Have you talked to your family about your wishes, values and beliefs about medical treatment in case you became seriously ill?

4. Have you spoken with a doctor about your wishes, values and beliefs about medical treatment in case you became seriously ill?

5. Have you ever had your wishes regarding medical care in the case that you became seriously ill, formally documented in an Advance Care Plan or Directive?

Prompts for the practice nurse:
- If so, – is a copy in the patient record?
- – when was it last reviewed?
- – where do you keep a copy?

If answer to Q5 is ‘no’, go to Q6, 7, 8; otherwise go to Q9

6. Have you ever heard of Advance Care Planning or Advance Care Directives?

7. Would you like an information brochure about Advance Care Planning?

Prompts for the practice nurse:
- If so, – has a copy of this been provided?

8. Would you be comfortable if a member of the practice were to further discuss advance care planning with you?

9. Is there anything else you would like the practice to know about your wishes or priorities when it comes to your health care?

10. Would you like to discuss these topics again with a family member or friend present?

Prompts for the practice nurse:
- If so, – who and what is this person’s relationship to the patient?

11. Please rate your level of comfort with our conversation today

Very Comfortable
Somewhat comfortable
Uncomfortable

Prompt for the nurse:
- Was the patient’s person responsible present during the screening interview?
- Was anyone else present?
- If so who and what is their relationship to the patient?
- Time taken to complete the interview?
- Write a note about anything else of relevance that comes up during the screening interview

Notes for Interviewer

Possible introduction sentence
As part of the senior’s annual check-up, we ask everyone about their future health wishes. Are you ok to talk with me about this for 5–10 min?

Helpful explanation re ACP
Advance Care Planning is a process that helps you to plan for future medical care. This process involves thinking about your values and beliefs and your wishes about the medical care you would like to have if you became critically ill or injured. It is a way to make sure that people involved in your life understand your wishes about medical treatment and care. You may choose to write down an Advance Care Directive that records your specific wishes in the event of serious illness, and any treatments you would refuse.

Person responsible
In New South Wales, if a person is unable to consent to a treatment, a ‘person responsible’ is able to consent to or decline treatment being offered to the person. The ‘person responsible’ is a legal term (Guardianship Act of 1987, NSW, Sect 33A, http://www.legislation.nsw.gov.au/inforce/580b32d3-f8fd-4a1f-dc87-c6d1f165a95b/1987-257.pdf, accessed June 2016). There is a specific order of people who the healthcare team must ask to be involved in medical decisions if the person themselves does not have capacity to make them. The person responsible is either:

(1) An enduring guardian (see above), if none then
(2) The person’s most recent spouse or de facto spouse, if none then
(3) An unpaid carer, if none then
(4) A close relative or friend with whom the person has an ongoing relationship

^Reproduced with permission from Josephine Clayton, the lead author of the Advance Care Planning Screening Interview tool.

Please note, since completion of this study, this Advance Care Planning Screening Interview tool has been further refined to be relevant to all states and territories of Australia, and incorporated into a toolkit and multicomponent training program for primary care clinicians called the Advance Project. The refined tool is available in electronic versions that can be incorporated into general practice medical records software, and is freely available from www.theadvanceproject.com.au. Advance Care Planning Screening Interview tool © 2016.