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Clinical assessment of decision-making capacity in acquired brain injury with personality change

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Assessment of decision-making capacity (DMC) can be difficult in acquired brain injury (ABI) particularly with the syndrome of organic personality disorder (OPD) (the “frontal lobe syndrome”). Clinical neuroscience may help but there are challenges translating its constructs to the decision-making abilities considered relevant by law and ethics. An in-depth interview study of DMC in OPD was undertaken. Six patients were purposefully sampled and rich interview data were acquired for scrutiny using interpretative phenomenological analysis. Interview data revealed that awareness of deficit and thinking about psychological states can be present. However, the awareness of deficit may not be “online” and effectively integrated into decision-making. Without this online awareness of deficit the ability to appreciate or use and weigh information in the process of deciding some matters appeared absent. We argue that the decision-making abilities discussed are: (1) necessary for DMC, (2) threatened by ABI, and (3) assessable at interview. Some advice for practically incorporating these abilities within assessments of DMC in patients with OPD is outlined.

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INTRODUCTION

Assessment of mental capacity or “competence” is part of the medico-legal landscape in many jurisdictions. Reflecting the decision-specific nature of the concept, the international literature is increasingly using the term “decision-making capacity” (DMC) and we use this term here. Clinical-ethical research has started to clarify how DMC relates to the type of psychiatric or neurological disorder (Kim, 2010; Owen, Freyenhagen, Hotopf, & Martin, 2015; Owen et al., 2013; Tan, Hope, Widdershoven, McMillan, & van der Scheer, 2008).

Patients with acquired brain injury (ABI) can present challenges for the assessment of DMC (*Masterman-Lister v. Brutton & Co.* [2002]) (Rose, 2003). This is particularly true of the subset of ABI patients with frontal brain injury and organic personality disorder (OPD)—sometimes called the “frontal lobe syndrome” (F07.0; *The ICD-10 Classification of Mental and Behavioural Disorders*, 1992). The primary tool in DMC assessment is the interview but the forms of dysfunction associated with this group may manifest more readily outside the interview than in it—particularly as impulsive or unwise decision-making—and during the interview patients may appear surprisingly unimpaired.

Clinical neuroscience may help. Indeed, it could be argued that human neuropsychology was born with Harlow’s description of the effects of an acquired brain injury to a certain Phineas Gage (Harlow, 1848). Since then, a number of striking examples of changes in behaviour, demeanour, attitudes and beliefs following damage to the frontal lobes have been made which have helped refine the notion of executive functions (Stuss, 2011). Within such functions, decision making itself has become a topic of considerable research effort (Ernst & Paulus, 2005). However, difficulties remain in measuring impairment in patients with executive dysfunction or OPD (Crawford, 1998). There is also the challenge of translating the norms of neuropsychology, which provide information about the prevalence of traits and deficits in populations, to the norms of law which relate to individual cases (Morse, 2010).

So although cognitive assessment is a valuable tool, for DMC assessment in ABI it does not translate directly. This is particularly true when the “appreciation” or “use and weigh” abilities to which the law refers may be in doubt. Dreer, Devivo, Novack, Krzywanski, and Marson (2008) conducted a study of DMC in patients with ABI reporting that measures of executive

impairment correlated only weakly with a legal standard of appreciation ability. The authors remark that appreciation remains particularly difficult to model using neuropsychological measures.

A further challenge is the legal principle that a person with disability must not be treated as unable to make a decision merely because he/she makes an unwise decision—Mental Capacity Act (2005) Section 1(4). It is the decision-making process that must be assessed. But in ABI, it is often the fact of unwise decision-making that is the salient factor and significant concern. How are unwise decisions made with DMC to be distinguished from unwise decisions made without in persons with ABI?

Here we focus on constructs from the cognitive and social neurosciences that seem to us to be closely allied to the “appreciation” or “use and weigh” abilities in DMC. The first concerns awareness of deficit in ABI. Awareness of deficit overlaps with insight—for which there are various conceptualisations (Amador & David, 2004). We are using the term awareness in the sense of first personal awareness. Lack of awareness of deficits can be extreme, amounting to anosognosia, but partial deficits are more common, particularly following diffuse injury or damage. One useful research methodology is based on questionnaires, with both patients and informants providing numerical ratings of the same abilities and behaviours. Patients with ABI characteristically tend to rate their own psychological abilities (cognitive, emotional, social) higher (and deficits lower) than do the informants with average discrepancy scores much greater than in healthy controls. Using this methodology, a quantitative measure of lack of self-awareness can be derived (Bach & David, 2006; Prigatano, 1992; Teasdale et al., 1997) which correlates neuropsychological tests and other clinician-rated measures of awareness. A similar discrepancy measure can be derived between the objective and subjective measures of a particular function as described above (Gilleen, Greenwood, & David, 2010).

A second research paradigm, which partly overlaps with the first, involves the concept of “metacognition”. Metacognition has been defined as “knowledge or cognition about cognitive phenomena” (Flavell, 1979) or “thinking about thinking” (Frith, 2012). The core is ability to think about and reflect upon cognitive processes (David, Bedford, Wiffen, & Gilleen, 2012), and a body of descriptive research has shown that metacognition can be impaired in ABI (Ciurli et al., 2010; Hanten, Bartha, & Levin, 2000; Langan-Fox, Grant, & Anglim, 2007; Ownsworth & Fleming, 2005).

The aim of our study is to translate between these recent neuroscience constructs and the “appreciation” or “use and weigh” abilities in DMC law in order to improve practical strategies for DMC assessment in patients with OPD. The task of translation, or transposition, we took to be interpretative and requiring close scrutiny of in-depth interview data from patients with ABI and OPD.

METHODS

A qualitative method was considered suited to develop concepts in a complex area that remains only partially theorised (Creswell, 2007). The study integrated clinical and phenomenological approaches with standard techniques from qualitative interview research. Further details on the method are reported elsewhere (Owen et al., 2013). Essentially, a series of open-structured interviews was used in order to gain insight into the patient's experience of making decisions under conditions of neuropsychiatric disorder. This was used as a basis for interpreting abilities needed to decide for oneself—the meaning of ability in DMC law and ethics. We sought abilities that may be lost or at risk of loss and which are assessable at interview.

The interviews covered the decision to participate in the research study itself and decisions concerning the person's treatment/care. Two interviews spaced across a few days were held, each lasting 1–2 hours. Recordings, coded transcripts and clinical sources of information (which included collateral sources) were submitted to close, iterative interpretative scrutiny. Excerpts from the interviews cited in this article are drawn from a large corpus of data. We used Atlas.ti software to facilitate analysis.

Sample

We followed the approach of Interpretative Phenomenological Analysis of purposely sampling around six cases to allow in-depth study of a relatively homogenous group (Smith, Flowers, & Larkin, 2009). Six patients with acquired brain injury (ABI 1–6) satisfying ICD-10 criteria for organic personality disorder (F07.0) and DSM-5 criteria for personality change due to acquired brain injury (310.1) were recruited. Participants were inpatients in neurorehabilitative settings in the UK except one who was on an old age psychiatric inpatient ward. All had histories of poor decision-making and expressions of concern from others regarding DMC.

Cases were selected without co-morbid psychiatric or neurological illness, pre-morbid personality disorder or where alcohol or drug use were current problems. Time since brain injury ranged from 1–19 years.

Table 1 gives characteristics of the participants. Attention, memory and language performances were relatively preserved for all participants except for one (ABI 6) who had memory impairment. Performance on the Hayling and Brixton tests of executive functioning or the Dysexecutive Questionnaire (DEX) was impaired but no individual test was impaired in all subjects. Each subject spoke English as a first language; education, work histories and scores on the National Adult Reading Test (NART) suggested average pre-morbid intelligence. The neurological histories and neuroimaging reports indicated damage predominantly to the frontal lobes. Each participant was able to

TABLE 1
Characteristics of sample

	<i>ABI 1</i>	<i>ABI 2</i>	<i>ABI 3</i>	<i>ABI 4</i>	<i>ABI 5</i>	<i>ABI 6</i>
Neurology	Haemorrhagic stroke following rupture of left frontal AVM.	RTA requiring right decompressive hemicraniectomy and evacuation of subdural haematoma and contusions.	Subarachnoid haemorrhage and complications of anterior communicating aneurysm clipping.	RTA with conservative management of closed head injury.	RTA with conservative management of closed head injury.	Haemorrhagic complications of pituitary surgery. Right frontal craniotomy.
Age	80	25	59	30	45	50
Sex	M	M	M	M	M	M
Ethnicity	White Irish	White British	White British	White British	White British	Black British
Legal status	Informal	Informal	Informal	Hospital order (from criminal court)	Hospital order (from criminal court)	Informal
Hayling sentence completion test	Poor	Impaired	Moderate average	Impaired	Poor	Average
Brixton spatial anticipation test	Impaired	Impaired	Impaired	Very superior	Good	Poor
DEX ^a discrepancy score	-3	3	20	39	-6	38

(Continued)

TABLE 1 Continued.

	<i>ABI 1</i>	<i>ABI 2</i>	<i>ABI 3</i>	<i>ABI 4</i>	<i>ABI 5</i>	<i>ABI 6</i>
Behaviour since injury	Anxious. Wife says "I'm now living with someone I don't know". Rigid, swearing.	Crude sexual and racial remarking. Mother says, "Some days he's this person I don't know".	In supermarket piled items in trolley and became foul-mouthed when suggested he look at costs. Tried to pay cashier with his bus pass and falsely accused cashier of trying to hold the line up.	Sexual behaviour in public. Exposed his erect penis to female neighbour out on driveway.	Slow, perseverative speech, rigidity, indecisive. Set furniture on fire at home.	Confabulates. Apathy. Walks into the bedroom of a fellow patient and urinates in sink.

AVM = arterio-venous malformation; RTA = road traffic accident.

^aHigh discrepancy value represents low insight into behavioural problem.

express choices; information about the relevant decisions was easily communicable to the participants and retained for periods sufficient to allow discussion.

Interviews

The clinical case assessments and interviews were conducted by GO, who has experience of research interviews involving DMC and is a consultant adult and liaison psychiatrist registered in the UK.

Research Ethics

The study received research ethics approval from the South East London Research Ethics Committee. The Mental Capacity Act (2005) rules for research were followed.

RESULTS

Awareness of deficit and thinking about thinking

Patients did show evidence of awareness of deficit and thinking about thinking at interview. This phenomenon is important to make explicit at the outset and attests to the challenge of DMC assessment in this group and the problems that have been reported about face-to-face interviews.

The awareness could be extensive in scope: of physical problems ranging from physical weakness through to non-specific feelings of being unwell, as well as psychological problems such as irritability, disinhibition or even paranoia. It was also surprisingly insightful and deep. A few excerpts from the transcripts illustrate the finding:

- 1 ABI 4: I've got a worse temper.
Interviewer: More of a temper?
ABI 4: Well I used to have a bad temper before but I'd go all day long before I'd lose it—but now it's five minutes and it's gone, you know.
- 2 ABI 2: I know I'm a bit crazy, paranoid about things like that. If you only knew the paranoia I go through in case like people stole my keys and put cameras in my workshop and things.
- 3 Interviewer: Yeah, what else changed that you weren't aware of?
ABI 5: That I wasn't aware of? Er ... I suppose that ... er ... [long pause] ... how disinhibited I was.
- 4 ABI 3: I get irritated quicker. Like "Oh, come on, let's go", you know? I'm like that, which isn't good.
Interviewer: Yeah. And that's following the subarachnoid haemorrhage?
ABI 3: Yeah. I never used to be like that. I've got such a short temper.

We also found evidence that patients were able to think about and reflect upon cognitive processes. For example, excerpts 5 and 6 below show thinking about one's own cognitive processes with excerpt 5 also showing thinking about the cognitive processes of others.

- 5 Interviewer: And you said at first you weren't aware there was a change.
 ABI 4: No I felt like myself but everything was different to friends. I didn't realise ... that I had actually changed. And when I realised that I had changed I moved away. My old mates ... everyone knew me before, everyone knew me as I was.
- 6 ABI 4: Definitely. I'd find it harder to stick to stuff than what I did before. Before, if I decided something then I could stick to it quite well, but now when people start to explain this and that is better ... I find that hard to ... Do you understand? ... I can't stick to things like I used to.
- Interviewer: Yeah, I thought that might be. So there's this sort of sense that even when you think that something's a good idea, it's still difficult to commit to it?
- ABI 4: Even when you're adamant about something, it's too easy to opt out of it.

However it was necessary to distinguish the appropriate engagement in thinking about cognitive processes from the results of the process, which may be error-prone:

- 7 Interviewer: And you know Dr F.—who's my colleague here—he's been listening in and thinking about what you've been saying.
 ABI 2: He's probably been laughing at what a dickhead I am, really.

Retrospective, concurrent and on-line awareness

Often the descriptive data from interviews did not do justice to the extent of the patients' difficulties. To compensate for this we found it useful to draw on an older research tradition (Lhermitte, Pillon, & Serdaru, 1986, p. 326; Goldstein & Scheerer, 1941; Lhermitte, 1986, p. 335). This focused on the ways in which patients with OPD navigate what we shall refer to as *the decision situation*. The starting point here is that decision-making does not take place narrowly "in the head"; it takes place *in the world*, and involves navigating a decision situation populated with options, opportunities, dangers, temptations, and other people.

We have already seen that ABI 4 exhibited both awareness of deficit (see excerpt 1, above) and thinking about thinking (excerpts 5, 6). But this was exhibited outside the decision situations in which they might (or might not) have been exercised. In following up with ABI 4, we asked him to reflect on past decision-making episodes—in particular the decisions associated with his discharge from hospital. Here a distinctive pattern came into view.

- 8 ABI 4: It was really weird because in the hospital, everyone else was really bad. Like they couldn't walk or talk, totally mute . . . But I was fine, I was walking and talking, and I thought everything was fine. And when I went home, I was like gone. I couldn't walk, couldn't walk upstairs. I was stuck in bed, and I couldn't talk, you know . . . It's nuts, isn't it? But when I was walking and talking I was fine. Every single day in the hospital I was asking if I could go home. "I want to go home, I want to go home. I'm fine, look at me. You can see I'm fine." So eventually they gave in and said, "Go on then, go home". And once I was home it was just different, you know. Before that I'd felt like I was better, I was fine . . .
- Interviewer: So when you were in hospital you felt it was all ok, you were walking around, you could speak, think, express yourself . . . ?
- ABI 4: I was feeling fine, . . . but once I got out of hospital I realised how bad I was.
- Interviewer: Outside of hospital it didn't work out?
- ABI 4: No, that's when I realised how bad I was.

Notice first that there is a sense in which this exchange itself exhibited both awareness of deficit and thinking about thinking. Within the context of the interview situation, and hence retrospectively, ABI 4 was showing awareness of some of the deficits associated with his injury—specifically, the inability to know whether he is really “fine”—and he was able to reflect on the process of thinking that led to his decision to be discharged. But the account he gave of the original decision situation itself is very different. In trying to orient himself in the decision situation, ABI 4 lacked insight into his own deficits, and so was unable to incorporate information about his deficits in the decisions about discharge, support, and place-of-residence. ABI 4 was himself clearly aware, but only retrospectively aware, of this deficit.

- 9 Interviewer: So this thing about not being able to see it at the time . . . not being able to see something at the time. I guess sometimes other people can see it at the time, but –
- ABI 4: Yeah if you're outside looking in you can see things, can't you, but on the inside you can't see it.

The exchange with ABI 4 suggested a first refinement in the use of “awareness of deficit” as a category in assessment of DMC. At a minimum, we need to distinguish between *retrospective* and concurrent awareness of deficit. In order to be relevant to DMC, awareness of deficit must be *concurrent*; that is, the awareness must be present at the material time when the decision needs to be made. Merely retrospective awareness may manifest itself in an assessment interview, but does not of itself contribute to DMC.

Another observation about this exchange with ABI 4 brought out a further issue. As the interviewer probed the patient's capacity to make decisions about place of residence, the exchange itself took on the form of a decision situation.

- 10 ABI 4: I want to get out, have a fresh start where no one knows me, and I don't know anybody, and start all over again. Start totally fresh, start a totally fresh life, a totally fresh life.
- Interviewer: And when you think like that, do you want to do it by yourself, alone, or do you want help from others?
- ABI 4: Do it myself.
- Interviewer: Do it yourself?
- ABI 4: Yeah. I mean my uncle, when he got out of the nick ... 9 years or 10 years ... He's out now, he's living up north ... When I get out of hospital I could go and see him ...
- Interviewer: So what you're saying is that what you prefer is to start again, without any help from others. That's very, very different to hospital, isn't it, where there's an enormous amount of help that you're getting.
- ABI 4: I don't need this bollocks [hospital care], I'm sick of it.

As the patient was deliberating about what to do, his awareness of deficit (and the associated recognition of the need for support) seemed to dissipate. So even in the context of an interview in which he had shown awareness of deficit regarding retrospective decisions, the patient showed an inability to *use* that information to navigate the challenges of the decision situation regarding his future. This in turn suggested that the relevant variable in awareness of deficit was not simply concurrence.

The importance of this point was shown in an exchange with another patient in the study:

- 11 Interviewer: I mean, for example, in the restaurant you had somebody kind of shout at you after you got irritated and you kind of got into an argument which had got a bit out of hand, and it sort of started because, whereas before you would have managed the situation, now you lose your temper?
- ABI 3: Yeah.
- Interviewer: Can you think of examples like that?
- ABI 3: Yeah it does happen. It does happen. [Noise from another patient in background.] I'll go out there and punch her on the f***ing nose in a minute if she don't shut up!

Here, ABI 3 showed explicit awareness of deficit, and thinking about thinking, particularly as regards control of his temper. But even in the very act of expressing this awareness, he engaged in the behaviour that reflected the deficit. Concurrence in the awareness of deficit may well be a *necessary* condition for DMC, at least as regards certain classes of decision; but it is not a *sufficient* condition. In order for awareness of deficit to contribute to DMC, it must be accessible "online" as well as concurrent. That is, the awareness of deficit must be effectively integrated into the decision-making process. For as ABI 3 demonstrated rather vividly, concurrent awareness of deficit and thinking about thinking can fail to inform the patient's navigation of the decision situation. This was a

phenomenon that we found reflected in other exchanges in the interviews, particularly with research subject ABI 2:

12 ABI 2: Yes. Again I do apologies [sic] for it [swearing/racist and sexist remarks]. I apologise every time—I spend two hours a day apologising. I just get bored with it. I know it's outrageous and disgusting. I know it offends a lot of people but I just can't stop it.

This phenomenon relates to forms of anosognosia neuropsychologists have attempted to model (Agnew & Morris, 1998). It also provides evidence of an impairment or even lack in the ability to learn from repeated unwise decisions or behaviour and adjust one's responses accordingly, arguably an analogue of perseveration—ABI 4 could not learn from the past episode about this need for care arrangements (see excerpt 8) when it came to making decisions regarding the future (see excerpt 10), since awareness of the former dissipated when the interview shifted to the latter; ABI 3 could not integrate his awareness of his bad temper in a way that led him to suspend his behaviour (excerpt 11); and ABI 2 reported he was unable to stop himself from doing something he clearly condemned (excerpt 12).

DISCUSSION

This study has shown that awareness of deficit and “thinking about thinking” can be present without being effectively available for use in decision-making. We suggest that this has implications for the “appreciation” and “use and weigh” abilities that law and ethics refer to and helps us to refine understanding of these abilities.

What about emotion in relation to the decision making of patients with OPD? Considerable attention has been devoted to this topic in the neuroscience literature and an influential approach has focused on the so-called “Iowa Gambling Task” and the “somatic marker hypothesis”. Emotion (operationalised as anticipatory skin conductance), it is hypothesised, aids healthy decision-making by providing positive or negative “biasing” of some options over others in a gambling task and this biasing is diminished in patients with damage to the ventromedial frontal lobe (Bechara, Damasio, Damasio, & Lee, 1999; Bechara & Van Der Linden, 2005).

Our data did not suggest that patients with OPD lacked emotion in relation to decision-making *in general*. We certainly did not find the patients emotionally cold in relation to decision-making. Indeed much of the interview data was tagged using a “sentimental” code. But, consider this example from ABI 2:

- 16 ABI 2: When I was younger, like about 15, if I hurt a woman I couldn't square . . . I used to get a bad feeling in my heart, I just couldn't do it. Now—I was trying the other day—I don't get those feelings. I just say "c****". I just don't get any feeling that I'm being bad or naughty.

Notice that ABI 2 was here reporting on the absence of a distinctive set of feelings that had once served to guide and constrain his behaviour. ABI 2 was not lacking in moral knowledge. Retrospectively he was able to identify and articulate what was inappropriate in his behaviour. But moral feelings were reported as absent prospectively and failed to orientate him to what might be regarded as the "value complexity" of the decision situation. Similar reports were given by other subjects in the study and the phenomenon is analysed further elsewhere (Owen, Freyenhagen, & Martin, *in press*). However, our data were not conclusive here and further research is called for.

Limitations

Studies using interpretative methods aim to be hypothesis-generating or illuminating in areas where measurement is inadequate or incomplete. In OPD, where the gap between cognitive tests/rating scales and DMC is especially large, and where guidance on assessment of DMC is sparse, this method is indicated. Studies of this type are always contestable. Our small sample was limited by including only male cases and there was no comparison group. Although all cases were out of the acute phase of brain injury, there was a wide range of time since injury and a diverse set of injuries to the brain. Despite these limitations the sample reflected the kinds of challenges this group pose to clinicians and courts and our method employed interpretative scrutiny involving diverse perspectives. In depth study of real cases can help illuminate the abilities relevant to the assessment of DMC (Owen, Freyenhagen, Richardson, & Hotopf, 2009). This study has shown that awareness of deficit can be present without being effectively available for use in decision-making. Further research should develop tools to capture this phenomenon.

ADVICE FOR ASSESSMENT OF DMC IN OPD

In light of these results we offer some advice on tailoring assessment of DMC to patients with OPD. This is not a definitive or comprehensive guide but a research-based contribution to improving DMC assessment in difficult cases of OPD where tools to aid assessment are currently lacking or vague (Freedman, Stuss, & Gordon, 1991).

Following Kim (2010) we find it useful to divide assessment into steps before, during and after interview.

Before interview

The law operates a presumption of DMC and there needs to be valid concern, or “triggers” to initiate DMC assessment in the first place. What are the triggers for DMC assessment in this group? We suggest that repeated “unwise” decisions, or failure to learn from mistakes, discrepancies between a patient’s self-evaluation of ability and those of others, collateral history of a “change in personality”, and measures of executive impairment on neuropsychological batteries should be considered as indicators of concern about DMC in patients with ABI. These indicators will come from consultation with others who know the patient. The difference between what the patient perceives is the problem and what others perceive is the problem may track the abilities we consider here but the discrepancy framework is insufficient for determining whether or not DMC is present. DMC law safeguards individuals’ ability to decide for themselves and an assessment must be able to distinguish between unwise decisions made with capacity and those made without.

Other questions that are relevant to consider before the interview are: (1) “What is the decision?” and (2) “What supportive structures are around the patient to help him or her decide (e.g., communication aids, strategies for compensating for attention difficulties, etc.)?”. The first question is important to answer so as to give the assessment the decision-specificity it requires but also to ensure that the assessor is clear that he/she understands what needs deciding about well enough to be able to communicate it simply and intelligibly. The second question is important because DMC law stipulates that a person is not to be regarded as lacking DMC unless all practicable steps to help the person make the decision for him or herself have not been successful. In cases where it is uncertain whether decision-making inability is due to ABI or to social barriers, it will become important to identify supportive interventions for that person that might overcome the barriers before judging lack of DMC (e.g., an advisor the patient trusts and who has an understanding of ABI or the removal of an undue influence on the patient). Also, in cases where the patient’s awareness may be expected to significantly improve with time or with rehabilitation (Prigatano, 1999), it will be important to consider whether the decision can wait until a time when the patient’s functioning is more optimal.

During

The DMC assessment, for a prospective decision, should be informed by face-to-face interview with the individual in whom DMC is a question. As already

mentioned, concern has been expressed by clinicians about face-to-face interview in these cases because of the way in which the deficits can elude structured assessment. But, following our study, we suggest that the interview can be adjusted to meet these concerns.

These themes can help orient the interview:

- Awareness of deficit: Is the person aware of deficits relevant to the decision that needs to be made? Does retrospective or concurrent unawareness mean he or she is unable to *understand or appreciate* the relevant information? If the person does have awareness of relevant deficits, is the awareness engaged or disengaged from the deliberative process? Is it online awareness? Is the person able to make *use* of his or her awareness in the context of deliberating?
- Detachment and disengagement: How does the person respond to his or her impulses in the context of decision-making and action? Does the person show an ability to “disengage” an impulse in order to consciously reflect? Does the person have the ability to resolve conflicting impulses that may arise in a decision situation? Is the person able to *use* a detached position in deliberation?
- Emotion: Considering emotion does ensure a broad approach but it needs to be handled with care. Assessors may ask, in facing the decision situation, to what extent are the person’s emotional responses suited to the situation, given the values he or she espouses? To what extent is the person able to *use* his or her feelings to navigate the value–complexity of the decision that is faced?

After

After the interview with the patient, interviews with others will be helpful to confirm or refute the evidence obtained on the abilities during the interview or to highlight areas of uncertainty. Those areas of uncertainty may require another interview, or more collateral sources of information, or trials of supporting the patient’s decision-making. Like all areas of clinical judgement, one stops the data gathering when there is enough evidence to form a judgement when a judgement needs to be made.

If the patient is considered to lack DMC, consideration will need to be given to it being regained, and the likely timescale.

Because the evidence obtained at interview is qualitative, we suggest conveying it in reports/written feedback using short extracts of dialogue that show the abilities or their absence. This can be supported with relevant evidence from collateral sources or from behaviour.

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