Promoting Assisted Decision Making in Acute Care Settings

Up to 6 players can take part in a game. The facilitator will guide players through the stages of the game, shown below.

## Full game (90 min)

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3 Reflection Players reflect on the discussions and how they relate to their own experiences, then fill out a perspective sheet. **(20 min)** 

# Quick game (40 min)

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### PlayDecide: PADMACS

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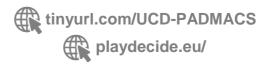
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Promoting Assisted Decision Making in Acute Care Settings

### **Guidelines**

- 1. You have a right to a voice: speak your truth ...
- 1. But not the whole truth: don't go on and on.
- 1. Value your life learning.
- Respect other people.
- 1. Allow them to finish before you speak.
- Delight in diversity.
- 1. Welcome surprise or confusion as a sign that you've let in new thoughts or feelings.
- 1. Look for common ground.
- 1. 'But' emphasises difference; 'and' emphasises similarity.

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Promoting Assisted Decision Making in Acute Care Settings



#### My position on assisted decision-making









Older adults

Healthcare professionals Policy makers

What key	learnings will	I take away f	from p	laying th	is game?
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I can apply these key learnings by ...





## PlayDecide: PADMACS

Promoting Assisted Decision Making in Acute Care Settings



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Older adults

**Family carers** 

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# Promoting Assisted Decision Making in Acute Care Settings



#### ABOUT THE ASSISTED DECISION-MAKING ACT

The Assisted Decision-Making (Capacity) Act 2015 provides new arrangements, procedures, guiding principles and structures for maximising the decision-making capacity of all. There is a statutory presumption that all individuals have decision-making capacity and shall not be deemed to lack that capacity unless all reasonable steps have been taken, without success, to help them.

#### IMPLICATIONS FOR PRACTICE

Under the Act, capacity is context and time-bound. This means that functional capacity is assessed on the basis of the person's ability to understand, at the time that a decision is to be made, the nature and consequences of that decision, in the context of the available choices at that time.

The Act provides a statutory framework of tiered decision supports appropriate to the level of decision-making capacity of the individual:

- 1) At the lowest level, a person may appoint a decision-making assistant to help him/her to obtain and assimilate information and communicate the decision
- 2) At the middle level, a person may appoint a co-decision maker with whom he/she may make decisions jointly
- At the upper level, the courts may intervene to make a declaration of incapacity in relation to certain matters and appoint a representative to act as a substitute decision-maker

The guiding principles of the Act place the will and preferences, beliefs, and values of the person at the centre of the decision-making process. Therefore, in making any intervention, an intervener must give effect to the past and present will and preferences of the individual. Where tiered decision support is in place for a person, an intervener must consider the views of any decision-making assistant, co-decision maker or decision-making representative. This pertains to healthcare interventions made by healthcare professionals.

The Act also provides for the establishment of the Office of the Decision Support Services which has regulatory and information functions.

(See https://www.mhcirl.ie/DSS/)

### PlayDecide: PADMACS

# Promoting Assisted Decision Making in Acute Care Settings



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Setup & info

**Discussion** 

# **Story Card** Info Card Place your chosen story card here



# Info Card

Place your chosen info card here



# **Issue Card**

Place your chosen issue card here

# **Issue Card**

Place your chosen issue card here





# **Key themes**

**SHARING INFO** Story cards 1 - 11

**CONTROL & POWER** Story cards 12 - 29

**RESOURCES** Story cards 30 - 41

**ENVIRONMENT** Story cards 41 - 54

**COMMUNICATION** Story cards 55 - 69

# Three stages of PlayDecide: PADMACS

### Full game (90 min)

Select a story card, find the linked issue cards, then select two info cards at random. Next, read the guidelines and information about the ADMCA on the placemat. (20 min)

Summarise your cards for the group, and identify and discuss themes and issues related to ADM, focusing on the perspectives and issues raised by the cards. (30 min) Next, share your own perspective and experiences relevant to the discussion. (20 min)

Reflect on the discussions and your own experience, then fill out a perspective sheet. (20 min) Reflection

### Quick game (40 min)

Select a story card, find one linked issue card, then select two info cards at random. Next, read the guidelines and information about the ADMCA on the placemat. (10 min)

Briefly summarise your cards, and identify and discuss themes and issues related to ADM, focusing on the perspectives and issues raised by the cards. (10 min) Next, share your own perspective and experiences relevant to the discussion. (10 min)

Reflect on the discussions and your own experience, then fill out a perspective sheet. (10 min)

# **Next steps**

#### Action

Think about how you can implement ADM in your working practice to fully incorporate the will and preferences of patients.



# PADMACS:

Promoting Assisted
Decision Making in
Acute Care Settings







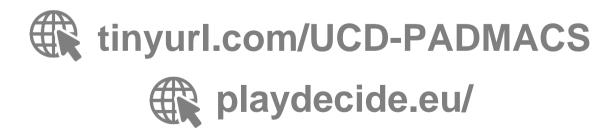












The role of carers in ascertaining a patient's will and preferences

Links to: Issue Cards (11)+(42)



Mary is a family carer of a person with a diagnosis of dementia.

My dad went in to the consultant and was told he needed eye surgery. He is currently on a waiting list. He has been told he could be waiting for a number of years. I am worried about what stage his dementia will be in a few years. I wonder will he be in a position to even consent to the surgery? I feel it is very important that the medical team includes family carers in the discussion about all the options. I am in the best place to ensure that the will and preference of my dad are respected when the time comes.



#### Access to the healthcare team

Links to: Issue Cards (13) + (21)



Tomás is an older person.

I was admitted to the ward from the ED with chest pain. I asked a few times to meet my consultant and her team but was told that it was not possible as they would only be 'flying through'. I finally met her and asked her to write down responses to my questions. She was really lovely and spent some time with me in the ward. I feel that often people are scared to ask for time with their doctor. I really had to insist to be given the information I needed. It should not be like this.



#### Alzheimer's diagnosis is not on file

Links to: Issue Cards (36)+ (47)



Róise is an older person with a diagnosis of Alzheimer's.

I have a short-term memory problem. I arrived into my local hospital with back pain. My Alzheimer's diagnosis was not on my file despite having been admitted previously. The team came to me the following day to advance my treatment. They mentioned that they had discussed all my options with me on the previous day. I had no memory of it. They had not spoken to my husband. I feel he should have been consulted so that he could support me to understand my options.





#### Repeating patient history

Links to: Issue Cards (35) + (40)



Lisa is a carer of an older person with a diagnosis of dementia.

I went to the emergency department with a family member who had recent multiple admissions to the same hospital. The doctor asked me for a verbal summary of my family member's case history. I found this stressful as I was afraid that I would forget important details. Why weren't details of her diagnosis and the medications on the notes from previous admissions? I now carry a list of medicines to hand over, but I find my anxiety increases every time.



When a patient has no capacity to understand information

Links to: Issue Cards (9)+(38)



Ben is a carer.

My wife Susan was receiving treatment for end stage cancer. On her last hospital stav, we knew she was very ill. I knew my wife was not going to live for long. I needed information to inform choices about her care in the final stages. I acknowledge the oncology doctor was very good in terms of the treatment he gave Susan, but his ability to communicate with us was terrible. He avoided talking to us. When asked for information, he refused point blank to give us any.



#### Having a plan

Links to: Issue Cards (39) + (47)



#### Enda is a doctor.

We had a man in his eighties admitted who had vascular dementia with multiple prior admissions. During the admission he raised the possibility that he may end up in a nursing home. So we discussed it further and he reviewed his options. He wanted to pick a nursing home that he could transfer to if needed at a later date. We supported his application to fair deal and the application form is on his file and will last for 6 months. It's a horrible conversation to have but a practical one.



Conversations about will and preferences may be difficult in the hospital setting

Links to: Issue Cards (21) + (22)



Sarah is a doctor.

We had a patient in the acute hospital setting who had a moderate cognitive impairment. He had experienced a catastrophic event causing him to be admitted. The patient expressed his wish to return home, but his family wanted him to be discharged to a nursing home. Our hospital is a very busy environment and the patient was a private man; he did not feel comfortable having discussions about his will and preferences in that setting. There is a risk that a patient's will and preferences might not get communicated clearly due to the hospital environment and conflicting opinions. He was discharged home and later re-admitted for a chest infection, before moving to a longterm facility.



Finding information about a patient's case is not always straightforward

Links to: Issue Cards (23) + (31)



Paul is a doctor.

We had a seventy-year-old patient in after a fall. She was living independently at home, divorced and estranged from her children. She had been diagnosed with new onset dementia but had been coping okay with a minor care package. She presented with a marked cognitive impairment and active hallucinosis associated with the type of dementia she had. She began to re-orientate herself and wanted to go home. However, she had almost no prior contact with the public service - all her care been private. There were no accessible notes on her care up to now. It took time just to establish the facts and ensure that she was being heard and supported during the decision-making process.



Consistent communication is needed to help advance care planning

Links to: Issue Cards 8 + 42



Aoife is a nurse

This patient was having repeated visits to hospital for what she believed was pneumonia, but the actual problem was recurrent aspiration due to reflux. She would not be well enough to undergo surgery to fix a hernia that was causing the reflux. However, I don't think this had been well explained to her. It turned out that a conversation with a doctor unfamiliar with the case had given her false hope that she would be well enough for the surgery soon. This caused a lot of confusion. The patient had capacity, but we needed to explain and repeat advice often. In the end she was discharged to a nursing home with the palliative care team's support. I think clear communication about the reality of her situation could have reduced confusion and delays in care planning.

SHARING INFORMATION





Preparing families around end-oflife care

Links to: Issue Cards (20) + (46)



Sean is a dietitian.

We were taking care of a patient with several medical complications and severe cognitive impairment. She was underweight and was refusing food. When she was first admitted, her family told us she had been eating well and had no cognitive issues, but this wasn't actually the case and in reality, she was reaching the end of her life. I requested involvement of the palliative care team, but the patient's family resisted. The rest of the team was busy dealing with her other medical issues and couldn't meet the family to help persuade them that it would be best to make her as comfortable as possible. I was the only one available to meet them and felt unsupported when trying to make the case. The patient passed away during her stay and we continued trying to feed her via nasogastric tube right up until the end.





Taking time to find out a patient's preferences

Links to: Issue Cards (26) + (38)



Jane is a dietitian

We have a patient who doesn't always follow advice from our team. and often argues with us about his care. He wasn't coping well at home and was refusing entry to meal delivery services. He was supposed to be following a diet to support his renal function. He told us he was doing well, eating plenty, and keeping active but based on our observations I suspected this wasn't true. After contacting his sister, we found out that he rarely ate, and seldom left the house. Nutritional support and supplementation was needed, but we needed to get the patient on-board with that idea. I engaged with him and his sister to get a better idea of his food preferences, and tried to accommodate these as much as possible so that he would feel comfortable and eat more. Lalso worked with him to find a nutritional supplement that he found acceptable.

SHARING INFORMATION

#### A communication plan

A formal approach to communication between the patient, decision-supporter, and healthcare professionals should be agreed at the outset of the care journey.



# Issue Card (9)

#### Communication training for healthcare professionals

ADM requires practitioners to be highly skilled and proficient in interpersonal communication. How can this be enabled?





# Communicating with nominated decision supporters and others

Sometimes there is tension between family members and healthcare professionals with respect to the patient's wishes. What is the difference between healthcare professionals' responsibilities to communicate with a nominated decision supporter as opposed to other family members, friends, or next of kin?





#### Patients' assertiveness

Patients can feel frustrated when their experience is not considered or valued in care planning. They may need to be quite assertive to make their voice heard. What could be done to maximise all patients' participation in the decision-making process?





#### Internal family conflicts

Internal family conflicts are a common source of stress for healthcare professionals when trying to support decisions of care. What strategies can they use to manage these conflicts?





#### The reality of the acute hospital

Some patients with complex needs require significant time in acute care to allow them to weigh up all the information necessary to make a decision about their care. How can we reconcile this within an environment operating key performance indicators that measure the length of hospital stay?





## Uninterrupted privacy and time, please!

Private space and time are crucial for healthcare professionals to support the capacity of patients in their decision making. The acute hospital environment often lacks the appropriate spaces and time to facilitate this.





## Environmental barriers to assisted decision making

What can healthcare professionals do to overcome social and physical environmental barriers in hospitals in order to maximise a patient's involvement in decision making?



**(26)** 

Therapeutic relationships are a key resource for quality ADM

Staff working in acute care services recognise the value of building a therapeutic relationship with the patient. Time pressure and competing workload can mitigate against this.



#### Can ADM be standardised?

What would a clinical guideline look like to support healthcare professionals to implement ADM into practice?





#### Difficulties in sharing healthrelated information

Often patients have to repeat their story many times and to many different professionals. This can be very frustrating and a cause of concern to them because details may be forgotten when they are asked to repeat them constantly. What could be done to improve the sharing of health-related information in the care planning process?



**36** 

The importance of making time to build and harness existing relationships with GPs

There are many demands and time pressures on healthcare staff in acute care settings. They may have little time to build positive and supportive relationships with patients and families. What can be done to involve GPs more in critical clinical and care decisions?



# Issue Card (38)

#### Amount and quality of information

Patients may have different information needs over their time in the acute setting. What can be done so that patients and their families always have the appropriate level and quality of information about their care and condition?





#### What matters to me

Admission to acute care settings can be a very stressful, disorientating, and frightening experience for any patient, especially for patients presenting with fluctuating capacity. Could knowing about likes and dislikes of that patient help reduce anxiety and discomfort?





#### Interprofessional collaboration

How can we enable good interprofessional collaboration which promotes the sharing of information required for assisted decision making?



**(42)** 

## Readiness to engage in care planning for the future

Receiving a formal diagnosis of dementia can be a very vulnerable time for the person. They may not be ready to engage in conversations about assisted decision making and care planning straight away. Is there a best time? What are your views on how this can be approached?





## Healthcare professionals can feel vulnerable

Some healthcare professionals recognise that there is a disparity between a patient's preferences to be cared for at home and the home care services available within the health system. Healthcare professionals may feel a sense of stress and helplessness.





#### Patients' will and preference

Early elicitation of patients' preferences and values is crucial for informing advance care planning. How can healthcare professionals encourage patients to share this information early on in their care pathway?



# Info Card 1

#### Assisted Decision-Making Act 2015

The ADMCA 2015 maximises the autonomy and dignity of persons who lack decision-making capacity in relation to one or more matters in the here and now, or who may do so in the future, by supporting them to make decisions based on their will and preferences.

# play

# Info Card 2

#### **Decision-making capacity**

"Decision-making capacity" is the ability to understand, at the time that the decision is to be made, the nature and consequences of the decision to be made in the context of available choices at that time.

# play

# Info Card 3

#### Provisions of the Assisted Decision-Making Act 2015

The provisions of the ADMCA apply to day-to-day and personal welfare decisions which include decisions about day-to-day living, finances, property, and healthcare treatment such as whether to consent to, or refuse, medical intervention.

# play

# Info Card 4

# Presumption of decision-making capacity

A person is presumed to have decisionmaking capacity in respect of the matter concerned. The burden of proving otherwise rests on the person who is questioning their ability to make a decision.

# play

# Info Card (5)

#### Screening

Screening for decision-making capacity involves a functional assessment which focuses on how a person makes a decision, as opposed to the nature or the wisdom of that decision.

#### Lacks capacity

A person can only be said to lack decision-making capacity if, at the point in time when they are being assessed, they cannot understand and retain the relevant information, do not believe the information, cannot weigh the information in the context of the decision-making process, and communicate their decision using whatever means they use to communicate.

#### Practicable steps have been taken

A person shall not be considered unable to make a decision for themselves unless all practicable steps have been taken, without success, to maximise his/her capacity and support him/her to make the decision. The nature of the support required will differ from person to person and depends on many factors.

#### **Steps**

Steps that support a person to make their own decision involve creating the right environment based on an understanding of the person, providing him/her with appropriate information tailored to his/her individual personality and needs, and providing tailored communication support.



#### **Unwise decisions**

People have the right to make decisions that others may not agree with. Believing a decision to be unwise is not a reason in itself to question someone's decision making capacity and is not evidence of a lack of capacity (although it may be indicative of this). People's values, beliefs and preferences differ.

### Info Card (1<sup>-</sup>

#### **Functional assessment**

The functional assessment of decision-making capacity is issue-specific and time-specific (the ability to make a specific decision at a particular point in time about a specific issue). Blanket assessments for capacity should not be made.

### No intervention unless necessary

Guiding Principle 4 – no intervention unless necessary. In so far as possible, there should not be any intervention by others in decisions made, or to be made, by a person whose capacity may be called into question in relation to a specific issue in the here and now, or at some time in the future.



#### Scope of the intervention

Guiding Principle 5 – the scope of the intervention should be limited so as to minimise the restriction of the person's rights and freedom of action. Due regard must be had to respect his/her rights to dignity, bodily integrity, privacy, autonomy, and control over his/her financial affairs and property.



### Intervention should be proportionate

The intervention should be proportionate to the significance and urgency of the matter, and the subject of the intervention (take into account the individual's circumstances, will and preferences, beliefs and values, and consider whether there is a less intrusive intervention available).



### Supporting decision-making

Guiding Principle 6 - Supporting decision-making requires permitting, encouraging, and facilitating, in so far as is practicable, the person to participate/improve his/her ability, as fully as possible, to make the decision, rather than having the decision made by someone else.



### Past and present will and preference

Supporting decision-making requires, giving effect to a person's past and present will and preference, taking into account his/her beliefs and values (that may have previously been expressed in writing) and considering the views of anyone named by the person to be consulted.



### **Enduring Power of Attorney**

A person who anticipates a future lack of decision-making capacity may enter into an Enduring Power of Attorney (EPOA), with another person, called their Attorney. The Attorney is authorised to make decisions in accordance with the terms of the EPOA, EPOAs are limited in so far as decisions pertaining to restraint of the person (unless exceptional emergency circumstances and conditions exist); the refusal of life-sustaining treatment and decisions that are expressed in an Advance Healthcare Directive, cannot be created/authorised by the EOPA.

#### Advance Healthcare Directive

An Enduring Power of Attorney (EPOA) cannot create/authorise a decision that has already been addressed by the person in an Advance Healthcare Directive (AHD) nor can it create/authorise a decision to refuse life-sustaining treatment, irrespective of whether an AHD exists. An EPOA cannot create/authorise a decision to restrain the person unless there are exceptional emergency circumstances and strict conditions apply.



### Losing decision-making capacity

A person who anticipates that they may lose decision-making capacity in the future may make an Advance Healthcare Directive (AHD) that expresses their will and preferences regarding medical treatment that may arise in the event of their losing capacity, for example, if they were to become comatose.

#### **Advance Care Directive**

The Advance Care Directive (ACD) may be a stand-alone directive or the person may appoint a dedicated healthcare representative (DHR) to exercise the powers conferred in the ACD. Significantly, a person may express their wish to refuse lifesustaining treatment through an ACD.

### Screening

Screening for decision-making capacity involves a functional assessment which focuses on how a person makes a decision as opposed to the nature or the wisdom of the decision.

#### Lacks capacity

A person can only be said to lack decision-making capacity if, at the point in time when they are being assessed, they cannot understand and retain the relevant information, do not believe the information, cannot weigh the information in the context of the decision-making process, and communicate their decision using whatever means they use to communicate.

#### Practicable steps have been taken

A person shall not be considered unable to make a decision for themselves unless all practicable steps have been taken, without success, to maximise his/her capacity and support him/her to make the decision. The nature of the support required will differ from person to person and depends on many factors.



### Three types of decision-making supports

The ADMCA provides for three types of decision-making supports: 1) Assisted decision-making, 2) Codecision making with individuals appointed by the person whose capacity is called into question, and 3) Where a person lacks capacity to make a decision with either of these supports, the court may appoint a decision-making representative or may make the decision on the person's behalf.

### Decision-making based on the interpretation of the known past

If the present will and preferences of the person cannot be ascertained after all practicable efforts have been tried, the ADMCA 2015 supports decision-making based on the interpretation of the known past will and preferences, taking into account the values and beliefs of the person as opposed to a third party deciding what is in the person's best interest.

#### Urgency around a decision

If there is urgency around a decision to be made, there may be less time to ascertain the person's will and preferences, values, and beliefs, but wherever possible, efforts should be made to do so. This could mean talking to the individual nominated by that person or their closest relation, partner or friend, who could help the person with communication or interpret signs that show his/her present will or preferences, or inform you about the person's last known will and preferences.

#### Role of close family

The role of close family members and next of kin is to guide healthcare and other professionals as to the will and preferences of the relevant person where that person lacks capacity to make the decision in question.

#### Role of Next of Kin

Generally, family members and next of kin of the relevant person do not have authority to make a decision on the part of that person unless they have been given authority to do so through the provisions of the ADMCA.

### Override a person's will and preference

It is a very serious step to seek to override a person's will and preferences by trying to impose an unwanted intervention. Such a person should be facilitated and enabled to challenge an unwanted decision, possibly by the appointment of an advocate.

#### Act in good faith

Anyone making an intervention on behalf of a person whose decision-making capacity is called into question must act in good faith (in accordance with professional codes of conduct or other applicable guidance) and for the benefit of the person which should be construed with references to their known will and preferences. What is/isn't of overall benefit to the person is unique to that person and should be understood in that way.

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### Judgement on a particular intervention

If it is not possible for the person to make a decision, even with support, and their will and preferences, beliefs and values, cannot be established, then a judgement is required on whether to proceed with a particular intervention. This should be informed by clinical/professional skill/experience and it is good practice to discuss the matter with other members of the multi-disciplinary team.

#### Third opinion

If there is disagreement as to whether a person has decision-making capacity in respect of a particular decision, it is good practice to seek a third opinion or convene a multidisciplinary meeting/case conference to discuss the issue. It may be necessary to refer the question to the Circuit or High Court.

#### Making an intervention

The person, e.g. a healthcare professional, who proposes making an intervention (an action or direction in respect of an individual whose decision-making capacity has been called into question) must be able to satisfy him or herself as to whether that individual has the capacity to make the decision. The healthcare professional may call upon colleagues to assist in assessing capacity.

#### Life-saving treatment

In situations involving life-saving treatment, where a person is found to lack decision-making capacity and it is not possible to defer treatment (to a time when they regain decision-making capacity or for their will and preferences to be ascertained), treatment may proceed.

#### Fluctuating decision-making capacity

In circumstances where a person has fluctuating decision-making capacity, non-urgent decisions should always be deferred to a time when their decision-making capacity is optimal.

#### Assessment

The assessment of decision-making capacity must be made by a registered medical practitioner and another healthcare professional in two circumstances: (a) the creation, variation, or revocation of an enduring power of attorney instrument, by applying a functional test at the time the instrument was created/varied/revoked, and (b) where the person wishes to create a co-decision-making agreement to appoint someone to jointly make decisions with them.

#### Called into question

A person whose decision-making capacity is called into question must consent to having their decision-making capacity functionally assessed. If the person is unwilling or refuses to consent to the assessment, steps may be taken to assist them, such as explaining the nature/purpose of the assessment, involving a trusted family member; listening to his/her concerns; providing time, support and reassurance.

#### Reasons for refusal

A person whose decision-making capacity is called into question may refuse to have their decision-making capacity functionally assessed and this, of itself, is not indicative of a lack of capacity. Their reasons for refusal should be documented and, if necessary, an application may be made to the Circuit or High Court for relevant orders.