

Submitted to Adults with Incapacity Amendment Act: consultation
Submitted on 2024-10-09 16:02:08

Part one: principles of Adults with Incapacity Act

1 Do you agree that the principles of the AWI Act should be updated to require all practicable steps to be taken to ascertain the will and preferences of the adult before any action is taken under the AWI Act?

Yes

Please give a reason for your answer:

We think that this is a positive change and that this ensures that an incapacitated adult's rights and preferences are considered. We agree with the principles and think that this puts the person at the centre of all decision making.

2 Do you agree that in the AWI Act we should talk about finding out what that adult's will and preferences are instead of their wishes and feelings?

Not Answered

Please give a reason for your answer:

3 Do you agree that any intervention under the AWI Act should be in accordance with the adult's rights, will and preferences unless not to do so would be impossible in reality?

Not Answered

Please a reason for your answer:

Part five: adapted section 47 certificate authorising removal of adult to hospital for the treatment of a physical illness or diagnostic tests where they are unable to consent to admission

36 Do you agree that the existing section 47 certificate should be adapted to allow for the removal of an adult to hospital for the treatment of a physical illness or diagnostic test where they appear to be unable to consent to admission?

Yes

Please give a reason for your answer:

This allows any incapacitated adult to be kept safe and able to access appropriate care and investigations necessary.

37 Do you consider anyone other than GPs, community nurses and paramedics being able to authorise a person to be conveyed to hospital? If so, who?

Yes

Please give further details to your answer:

We think that the amendments to the Act require to be future proofed. Suitable professionals include pharmacists practicing within community pharmacy and primary care locations. Pharmacists have close professional relationships with patients and can notice when patients require additional assistance. The pharmacy profession is evolving and in 2026, all pharmacists will be able to prescribe medicines once qualified. Expansion of roles including advanced pharmacist practitioners will also evolve the scope of care delivered in the future. These changes, alongside other reforms, including pharmacists ability to complete sick notes, means that the profession is changing and in the coming years, the role of the pharmacist will also change. Enablers such as access to an integrated health and social care record will mean that pharmacists are in an ideal situation to make informed decisions about whether an incapacitated adult requires conveying to hospital and should be added to the list of approved professionals.

38 Do you agree that if the adult contests their stay after arriving in hospital that they should be assisted to appeal this?

Yes

Please give a reason for your answer:

Yes, depending on the condition leading to the incapacitation, the person's capacity may fluctuate and in keeping with the principles set out in this document, a person's wills and preferences should be at the centre of the decision.

39 Who could be responsible for assisting the adult in appealing this in hospital?

Please give the reason for your answer:

Within the organisation where the patient is admitted, there should be an independent person who has not been involved in the care of the patient, or the decision to admit the patient.

An enhanced section 47 certificate to prevent a person being treated for a physical condition from leaving hospital, whether temporarily or permanently

40 Do you agree that the lead medical practitioner responsible for authorising the section 47 certificate can also then authorise measures to prevent the adult from leaving the hospital?

Yes

Please give a reason for your answer:

Whilst we support this principle, the patient journey through healthcare may be more complex and involve more people than the question suggests. For example, a patient may be admitted to an assessment unit and the clinician in charge of their care completes the Section 47 certificate. Once investigations are complete, the patient may then move to another clinical area where the treatment is handed over to another clinician.

We think that the medical practitioner authorising the Section 47 certificate may then authorise measures to prevent the adult from leaving hospital – as long as they remain the lead clinician for their care. If responsibility for care passes to another clinician, measures to prevent the adult leaving hospital must be described as part of the overall care plan and within the law it must be clear who holds responsibility under the Act at each point in the patient journey.

41 Do you think the certificate should provide for an end date which allows an adult to leave the hospital after treatment for a physical illness has ended?

Yes

Please give a reason for your answer:

42 Do you think that there should be a second medical practitioner (i.e. one that has not certified the section 47 certificate treatment) authorising the measures to prevent an adult from leaving the hospital?

Yes

Please give a reason for your answer:

We do not think that two medical practitioners need to be involved in each Section 47 certificate – however, the process must be able to accommodate more than one clinician being involved in a patient's care through their journey. E.g. from admission unit to downstream ward and further care as necessary.

43 If yes, should they only be involved if relevant others such as family, guardian or attorney dispute the placement in hospital?

Not Answered

Please give a reason for your answer:

44 Do you agree that there should be a review process after 28 days to ensure that the patient still needs to be made subject to the restriction measures under the new provisions?

Yes

Please give a reason for your answer:

For adults who have a long term or permanent incapacity 28 days seems reasonable. However, for those patients who recover, there needs to be a nimble, agile process which comes into place when necessary and which may be before the 28 day period is reached.

45 Do you agree that the lead clinician can only authorise renewal after review up to maximum of 3 months before Sheriff Court needs to be involved in review of the detention?

Yes

Please give a reason for your answer:

46 What sort of support should be provided to enable the adult to appeal treatment and restriction measures?

Not Answered

Please give the reason for your answer:

The timelines involved in any process must be efficient and clinicians involved must be independent of the admission and treatment decisions.

Clarifying the provision of palliative care under Part 5 of the AWI Act where a welfare proxy disagrees with proposed treatment

47 Do you agree that section 50(7) should be amended to allow treatment to alleviate serious suffering on the part of the patient?

Yes

Please give a reason for your answer:

This is essential to ensure that unnecessary suffering is prevented.

48 Would this provide clarity in the legislation for medical practitioners?

Yes

Please give the reason(s) for any of your answers to questions 47 and 48 above:

All of the processes described to overcome dispute take time and have the potential to delay treatment which relieves suffering of the patient at the centre of the dispute.

Part eight: proposals to amend the Adults with Incapacity Act in respect of the governance of incapacitated adults participating in research

91 Should the AWI Act be amended to allow the creation of more than one ethics committee capable of reviewing research proposals involving adults lacking capacity in Scotland?

Yes

Please give the reason(s) for your answer:

We agree that this would boost capacity within the system and support any appeals process.

We observe that two options are possible – an additional REC with specific expertise to review relevant applications but also (if more participation of AWI in all research) all RECs requiring to have the necessary training and expertise to review protocols where AWI will be included in prospective participants.

Permitting adults with incapacity to be included in research studies without consent for the types of studies where consent is already not required from adults with capacity

92 In research studies for which consent is not required for adults with capacity to be included as participants, should adults with incapacity also be permitted to be included as participants without an appropriate person providing consent for them?

Yes

Please give the reason for your answer:

It is important that research includes as broad a spectrum of the population as possible to reduce health inequalities and ensure valid research outcomes exist for all citizens. This removes adults with incapacity being prevented from participating in studies where the risk to the individual is negligible and the potential overall benefit could be substantial.

93 Should Scotland A REC (or any other ethics committee constituted under Regulations made by the Scottish Ministers in the future) have the ability to determine that consent would not be required for adults with incapacity to be included as research participants, when reviewing studies for which consent would also not be required to include adults with capacity as research participants?

Yes

Please give the reason for your answer:

Supporting the answer to Q92 we believe that the Scotland A REC is the appropriate body to make the necessary determination on a protocol by protocol basis.

Pathways for emergency waivers of consent

94 Should the Adults with Incapacity Act be amended to allow researchers to consult with a registered medical practitioner not associated with the study and, where both agree, to authorise the participation of adults with incapacity in research studies in emergency situations where an urgent decision is required and researchers cannot reasonably obtain consent from a guardian, welfare attorney or nearest relative in time?

Yes

Please give the reason for your answer:

Yes, this additional registered medical practitioner must not be associated with the study, however, as a safeguard, must be informed of the nature of the study and must have been involved in the care of the patient to understand the potential risks and benefits.

95 Should the Adults with Incapacity Act be amended to allow researchers to enrol adults with incapacity in research studies without the consent of an appropriate representative of the adult, in emergency situations where a decision to participate in research must be made as a matter of urgency, where researchers cannot reasonably obtain consent from an appropriate representative of the adult, and where researchers act in accordance with procedures that have been approved by Scotland A REC (or any other ethics committee constituted by regulations made by the Scottish Ministers)?

Yes

Please give the reason for your answer:

The key to this is the detail in the study protocol outlining the safeguards which would allow the SAREC or equivalent to make the necessary determination.

The positive aspect of these changes is that adults with incapacity are not broadly prevented from accessing an intervention which may be of benefit to them or may contribute to learning which may benefit the wider population in future.

Expanding the list of approved persons who can provide consent for adults with incapacity participating in research

96 Should the Adults with Incapacity Act be amended to permit researchers to nominate a professional consultee to provide consent for adults with incapacity to participate in research, in instances where researchers cannot reasonably obtain consent from a guardian, welfare attorney or nearest relative?

Not Answered

Please give the reason(s) for your answer:

Allowing adults with incapacity to participate in a wider range of research studies

97 In addition to being permitted to participate in research that investigates the cause, diagnosis, treatment or care of their incapacity, should the Adults with Incapacity Act be amended to allow adults lacking capacity to participate in research that investigates conditions that may arise as a consequence of their incapacity?

Yes

Please give the reason for your answer:

We think this is an important change and are supportive of this.

98 In addition to being permitted to participate in research that investigates the cause, diagnosis, treatment or care of their incapacity, should the Adults with Incapacity Act be amended to allow adults lacking capacity to partake in research that investigates conditions they experience that do not relate to their incapacity?

Yes

Please give the reason for your answer:

We support this change on the principle of broadening research participation and the validity of research outcomes which can apply across a wider proportion of the population.

99 Should the Adults with Incapacity Act be amended to allow adults with incapacity the opportunity to participate in any research regardless of whether the research explores conditions that relate to their incapacity or investigates conditions that they experience themselves?

Yes

Please give the reason for your answer:

As above

About you

100 What is your name?

Name:

Fiona McIntyre

101 Are you responding as an individual or an organisation?

Organisation

102 What is your organisation?

Organisation:

Royal Pharmaceutical Society Scotland

103 Further information about your organisation's response

Please add any additional context:

104 If you are responding as an organisation, please tell us which of the following categories best describes you?(select all that are appropriate)

Other (please say below)

Other (please say):

Professional body for pharmacy

105 What is your phone number?

please provide your phone number:

02075722226

106 What is your postcode?

postcode:

EH3 7HF

107 Which ethnic group best describes you?

Not Applicable – responding as an organisation

108 What was your age last birthday?

Not Applicable – responding as an organisation

109 Which local authority area you live in (or operate in if an organisation - tick all that apply)? Individuals should select only one.

110 Which of these options best describes how you think of yourself?

Not Applicable – responding as an organisation

111 Which gender identity best describes you?

Not Applicable – responding as an organisation

112 The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

113 Do you consent to Scottish Government contacting you again in relation to this consultation exercise?

Yes

114 What is your email address?

Email:

Fiona.McIntyre@rpharms.com

email address:

Fiona.McIntyre@rpharms.com

115 I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

116 Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Slightly satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Slightly satisfied

Please enter comments here.: