Adults with Incapacity Amendment Act Consultation

July 2024

Scottish Government
Riaghaltas na h-Alba

Adults with Incapacity Amendment Act Consultation

Ministerial Foreword

The Adults with Incapacity (Scotland) Act 2000 (AWI Act) when introduced was seen as a major step forward in incapacity legislation. Its rights based focus, centred around principles, earned Scotland an international reputation for being a leading example of a country that had created good legislative practice.

Since then there have been significant changes both in legislation and case law. The United Nations Convention on the Rights of Persons with Disability (UNCRPD) was ratified by the UK in 2009. The Convention sets out what should be done to break down the barriers that prevent disabled people from realising all of their human rights. European and Supreme Court rulings in the Bournewood and Cheshire West cases expanded the conditions where someone could be considered to be deprived of their liberty and therefore eligible for the protections offered under Article 5 of the European Convention on Human Rights.

To consider the impact of these changes on the AWI Act along with the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adult Support and Protection (Scotland) Act 2007, the Scottish Government commissioned an independent review, chaired by Lord Scott. The Scottish Mental Health Law Review (SMHLR) published its final report in September 2022. Since then we have formed a programme of change, publishing our delivery plan in June this year. Consultation on change to the AWI Act is an early action in this plan.

This consultation is the outcome of informal discussions with a wide range of stakeholders and service users who have given up valuable time over the last few years to meet with Scottish Government officials to discuss what works well about the law as it stands, and what needs to change. It also considers the recommendations the SMHLR made for early changes to the AWI Act.

I am very grateful to the time and effort so many have given to reaching this stage. This consultation gives the opportunity for a wider audience to let us know what works and what doesn't around the AWI Act, and what reforms might be needed to reflect the changes that have occurred in the past 20 years since the AWI Act came into force. Your time in considering this consultation is much appreciated and I look forward to seeing the results.

Maree Todd MSP
Minister for Social Care, Mental Wellbeing and Sport.

Introduction

This consultation is asking for your thoughts on proposals for reform to the Adults with Incapacity (Scotland) Act 2000 (the AWI Act).[1]

When the AWI Act was enacted in 2000, it was regarded as ground-breaking legislation. For the first time, Scotland had a comprehensive regime to protect the welfare and financial rights of persons lacking in capacity.

But international human rights law in this field has developed further since then and we need to ensure that Scotland's law remains fully fit for purpose.

In the past ten years the AWI Act has been the subject of much scrutiny. In 2014, the Scottish Law Commission in its report[2] made substantive recommendations for change around the issue of depriving persons with incapacity of their liberty. These recommendations were consulted on in 2016[3] and a further, more wide ranging consultation on AWI was carried out in 2018[4] by the Scottish Government.

Most recently, the position on adult capacity law was included in the remit for the Independent Review of Mental Health and Incapacity law (SMHLR)[5] which was announced by Scottish Ministers in 2019 and reported in 2022.

The strong recommendation of the SMHLR was a new overall approach to mental health and capacity law was required. The law should have a new purpose, namely to ensure that the human rights of people with mental or intellectual disability are respected, protected and fulfilled.

It was recognised in the final report of the SMHLR however that such a radical change would take several years to achieve and there was a pressing need for earlier reform to the AWI Act to address concerns around whether the AWI Act had kept pace with developments in human rights law, and the prospect of incorporation of the UN Convention of the Rights of Persons with Disabilities (UNCRPD)[6] into Scots law.

The Scottish Government agreed with the recommendation of the SMHLR.

---

[1] Adults with Incapacity (Scotland) Act 2000 asp 4

[2] Report on Adults with Incapacity - SLC 204 (scotlawcom.gov.uk)

[3] Scottish Law Commissions Report on Adults with Incapacity - Scottish Government consultations - Citizen Space

[4] Adults with Incapacity Reform - Scottish Government consultations - Citizen Space

[5] [ARCHIVED CONTENT] Homepage | Scottish Mental Health Law Review (nrscotland.gov.uk)

[6] The UNCRPD was ratified by the UK in 2009. It sets out the human rights of disabled people and the obligation on states to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities, without discrimination of any kind on the basis of disability.

This consultation seeks views on changes to the existing AWI Act. It builds on earlier work but recognises the fact that this is the first step in a wider programme of work to reform mental health and capacity law in Scotland over the next ten years.

Overview of the Consultation

This consultation and the reforms it proposes to the AWI Act are early actions in response to the recommendations of the Scottish Mental Health Law Review (SMHLR).

The purpose of the consultation is to seek views on updating the AWI Act in advance of wider reforms that may take place over the next 5 to 10 years, as set out in the Scottish Government's response to the SMHLR.

We are seeking views on suggestions for change to the AWI Act that aim to:

- Improve access to justice for adults affected by the AWI Act
- Shift the focus of the AWI Act to one that truly centres on the adult
- Enable adults to access rights more easily
- Ensure adults are supported to make and act upon their own decisions for as long as possible
- When an adult cannot make their own decisions despite support, ensure that their will and preferences are followed unless doing so would be to the overall detriment of the adult.

In addition part 8 of the consultation, which can be considered in isolation, sets out proposals for reform to section 51 of the AWI Act and associated regulations, concerning authority for research.

The consultation focuses on changes to the law. But for changes to the law to be truly effective, a change in practice and in particular the need to embed supported decision making across the health and social care sector needs to be acknowledged.

A key part of mental health and capacity reform is improving support to further embed a human rights based approach within services and wider systems of support. The initial delivery plan for the Mental Health and Capacity Reform Programme was published on 4th June. This outlines the early work being taken forward which will review and assess current approaches to supported decision making being taken forward across government, including work being taken forward around the National Care Service Bill to enhance independent advocacy as a means of empowering people to have their voices heard and realise their rights.

Alongside this, emerging policies such as Getting it Right for Everyone, and the work following the consultation on the proposed Human Rights Bill will strengthen person centred and rights based practice.

We will be assessing the progress of this work and over the coming months will be considering what else needs to be done to put in place a comprehensive supported

decision making regime that will be required to underpin proposed changes in AWI law.

Mental Disorder

Another early priority for work following the response to the SMHLR is consideration of the term ‘mental disorder’. This is the term used in both the AWI Act and the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act), to describe a person who could come within the remit of these Acts. It is considered by many to be outdated and offensive. Work has begun with partners alongside the consultation on a proposed Learning Disabilities, Autism and Neurodivergence Bill, to look at options for change. This topic is not part of this consultation but any recommendations for change emerging from the ongoing work will be considered in due course.

Contents

The consultation broadly follows the order of the AWI Act. Part 7 includes consideration of deprivation of liberty of an adult lacking in capacity. Whilst authority for research is in Part 5 of the AWI Act, we have included it as Part 8 of the consultation due to its size.

1. Part 1 - Principles of the legislation – changes to reflect the need to ensure that the wishes and feelings of the adult are front and centre at all times, changes in terminology (and other areas of Part 1 we are consulting on)

2. Part 2 - Powers of attorney – summary of changes previously consulted on that we are taking forward, other issues

3. Part 3 – access to funds – changes to make it more accessible

4. Part 4 - management of residents' finances - removal of sections

5. Part 5 – changes to s 47 certificates and associated matters

6. Part 6 – changes to guardianship, interim guardianship and intervention orders

7. Part 7 – deprivation of liberty proposals, stand-alone right of appeal, appointment of safeguarders

8. Part 8 – Authority for Research

GLOSSARY OF TERMS

"2003 Act" – The Mental Health (Care and Treatment) (Scotland) Act 2003

"Advocacy" - Advocacy means getting support from another person to help the adult express their views and wishes, and to help make sure their voice is heard. Someone who helps an adult in this way is called an advocate

"ATF" – Access to Funds. This is a scheme operated by the Office of the Public Guardian to access an incapacitated adult's funds

"Article 5 ECHR" – Article 5 of the European Convention on Human Rights relates to the right to liberty and security. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in certain cases and in accordance with a procedure prescribed by law

"The AWI Act" – The Adults with Incapacity (Scotland) Act 2000

"Caldicott Guardian" - An individual who is responsible for ensuring that personal health and social care data is processed and stored legally, ethically, and appropriately in an organisation

"Care Inspectorate" - The Care Inspectorate regulates and inspects care services in Scotland to make sure that they meet the right standards. They jointly inspect with other regulators to check how well different organisations in local areas work to support adults and children

"Court of Session" - The Court of Session is the supreme civil court of Scotland, and constitutes part of the College of Justice; the supreme criminal court of Scotland is the High Court of Justiciary. The Court of Session sits in Parliament House in Edinburgh, and is both a trial court and a court of appeal

"Clinical Trials Regulations" - Refers to The Medicines for Human Use (Clinical Trials) Regulations 2004

"CTIMP" - A Clinical Trial of an Investigatory Medical Product. Broadly speaking, these trials involve testing new medicines and drugs. In the UK, such trials are governed by The Medicines for Human Use (Clinical Trials) Regulations 2004. CTIMPs require approval from the Medicines and Healthcare products Regulatory Agency (MHRA) and guidance on how to apply for CTIMP authorisation in the UK (including on whether a research study should be classified as a CTIMP) can be found here: Clinical trials for medicines: apply for authorisation in the UK

"DOL" – Deprivation of Liberty

"ECHR" – The European Convention on Human Rights

"Faculty of Advocates" - The Faculty of Advocates is an independent body of lawyers who have been admitted to practise as advocates before the courts of Scotland,

especially the Court of Session and the High Court of Justiciary. The Faculty of Advocates is a constituent part of the College of Justice and is based in Edinburgh

“HRA” - Health Research Authority. The Health Research Authority is an arm’s length body of the Department of Health and Social Care of the UK Government.

“Identifiable Data” - If the identity of an individual can be ascertained from the data that has been provided by them, that data is said to be identifiable data.

“Investigational Medicinal Product” - Defined in The Medicines for Human Use (Clinical Trials) Regulations 2004 as:

> A pharmaceutical form of an active substance or placebo being tested, or to be tested, or used, or to be used, as a reference in a clinical trial, and includes a medicinal product which has a marketing authorisation but is, for the purposes of the trial—
>
> (a) used or assembled (formulated or packaged) in a way different from the form of the product authorised under the authorisation,
>
> (b) used for an indication not included in the summary of product characteristics under the authorisation for that product, or

(c) used to gain further information about the form of that product as authorised under the authorisation

“Law Society of Scotland” - The professional governing body for Scottish solicitors. It promotes the interests of the public in relation to the profession. The Society helps to shape the law for the benefit of both the public and the profession

“Lay Members” - People who are not employed in health or care professions, or whose primary professional interest is not health or care-related research.

“Medicinal Product” - The body that regulates medicines, medical devices and blood components for transfusion in the UK - the Medicines and Healthcare products Regulatory Agency (MHRA) - uses the definitions for Medicinal Product found in Article 1 of EU Directive 2001/83/EC: A Medicinal Product is:

“Any substance or combination of substances presented as having properties for treating or preventing disease in human beings; or

Any substance or combination of substances which may be used in, or administered to, human beings, either with a view to restoring, correcting or modifying physiological functions by exerting a pharmacological, immunological or metabolic action, or to making a medical diagnosis.”

MHRA guidance states that a product that falls under either definition is sufficient to be classified as a Medicinal Product.

“Mental Health Officer” - A mental health officer is a social worker who has special training and experience in working with people who have a mental illness, learning disability or related condition

“MHTS” – The Mental Health Tribunal for Scotland

“MWC” – The Mental Welfare Commission

“Non-CTIMP” - A research study which does not involve testing an Investigational Medicinal Product (as defined in The Medicines for Human Use (Clinical Trials) Regulations 2004)

“NRS” - NHS Research Scotland is an organisation that promotes and supports excellence in clinical and translational research in Scotland so that patients can benefit from new and better treatments.

“OPG” – The Office of the Public Guardian

“Section 22 Doctor” - A section 22 doctor is a medical practitioner approved by the local health board, or the State Hospital’s Board for Scotland for the purposes of section 22 of the Mental Health (Care and Treatment) Scotland Act 2003 as having special experience in the diagnosis and treatment of mental disorder

“PBPP” - Public Benefit and Privacy Panel. NHS Scotland body that scrutinises, reviews, and approves applications for accessing NHS Scotland data for non-direct care purposes (e.g. research).

“Research Ethics Committee (REC)” - Research Ethics Committees are the bodies within the UK Research Ethics Service that are responsible for reviewing research proposals that involve NHS patients, and protect the rights, safety, dignity and wellbeing of these research participants in the UK

“Scotland A REC (SAREC)” - The Research Ethics Committee which reviews research proposals in Scotland involving incapacitated adults. It is currently the only Research Ethics Committee in Scotland which is authorised to do so

“The Commission” – The Scottish Law Commission (SLC). The Commission is Scotland's law reform body. It was established under the Law Commissions Act 1965 to make recommendations to Government to simplify, modernise and improve Scots law

“The Regulations” - The Adults with Incapacity (Ethics Committee) (Scotland) Regulations 2002

“UNCRPD” – The United Nations Convention on the Rights of Persons with Disabilities

PART 1

PRINCIPLES OF THE LEGISLATION

Section 1(6) of the AWI Act defines a person over 16 as 'incapable' if they are incapable of:

- acting; or
- making decisions; or
- communicating decisions; or
- understanding decisions; or
- retaining the memory of decisions,

by reason of mental disorder or an inability to communicate due to a physical disability that cannot be improved by an external aid.

Furthermore, incapacity is not always permanent and the nature of an individual's incapacity can be dependent on the condition or illness they are experiencing. The reasons for incapacity can be incredibly varied, and may include conditions like dementia, severe trauma caused by accidents that render individuals unconscious, learning difficulties, mental states such as delirium, amongst many others. Incapacity can also be temporarily caused by a particular treatment regime received by an individual (e.g. patients being placed in medically induced comas).

The AWI Act is governed by principles set out in section 1 of the Act. Anyone taking action under the AWI Act has a legal duty to follow the principles.

The principles can be summarised as follows

- No one should intervene under the AWI Act unless they are satisfied that the action will benefit the adult. They should also be satisfied that this benefit cannot reasonably be achieved without the intervention
- Any action taken should be the minimum necessary to achieve that purpose.
- Anyone determining whether to intervene, and what intervention to make, should take account of the past and present wishes and feelings of the adult.
- The views of certain significant others in the adult's life need to be taken into account
- Any guardian, attorney or manager of an establishment should encourage the adult to exercise whatever skills they have and to develop new skills, as far as this is reasonable and practicable.

These principles all have parity. No single principle is more important than another and together they should ensure that all actions taken under the AWI Act stem from the needs of the adult. Everyone acting under the AWI Act must be able to justify their actions in accordance with the principles of the Act.

Since the AWI Act came into force, the principles have been considered to represent good practice and are generally well accepted. However, there is concern that,

considering the ratification of the UNCRPD by the UK, the principles do not go far enough to ensure the rights of disabled people are upheld.

This was highlighted in the final report of the SMHLR. The report recognised that if the complete agenda for legislative reform was adopted by the Scottish Government, it would take several years to develop, but that more urgent reforms were needed to the AWI Act.

Key to these changes was an updating of the AWI principles within the AWI Act, to place a greater emphasis on respecting the will and preferences of adults affected by the legislation. Chapter 13 of the final SMHLR report drew on the recommendations of the Three Jurisdictions report [7] as highlighted by the Law Society of Scotland.

The Three Jurisdictions report aimed to recommend steps that might be taken by Scotland, England, Wales and Northern Ireland to bring their capacity law regimes closer to achieving compliance with the UNCRPD and ensure respect for the rights of disabled people.

Central to this is consideration of article 12 of the UNCRPD which states:

Article 12 – Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

---

[7] The EAP Three Jurisdictions Report

The requirements of article 12 of UNCRPD mean that respect for the full range of the rights, will and preferences of everyone should lie at the heart of legal regimes. To move towards this, the recommendation of the SMHLR was that the principles of the AWI Act should be amended in line with the recommendations of the Three Jurisdictions Report to give greater priority to the will and preferences of the adult.

When we talk about rights, will and preferences we mean a person's longstanding values beliefs and goals, along with shorter term preferences for one choice over another. We think that this term should be used in legislation instead of wishes and feelings as it is used in the UNCRPD, and reflects more accurately the need to reflect both long and short term choices of the adult.

The SMHLR concluded that we should follow the recommendations of the Three Jurisdictions report. The Three Jurisdictions Report said

> '[there should be a] rebuttable presumption that effect should be given to the person's reasonably ascertainable will and preferences... Action which contravenes the person's known will and preferences should only be permissible if it is shown to be a necessary and proportional means of effectively protecting the full range of the person's rights, freedoms and interests'.[8]

We agree with this. At present section 1(4)(a) of the AWI Act requires the past and present wishes and feelings of the adult, so far as they can be ascertained, to be taken account of in determining if an intervention should be made, and what such an intervention should be. However this is on an equal footing with the requirement to take account of the views of the nearest relative, guardian, attorney, named person or any other person who might have an interest in the welfare of the adult, or the proposed intervention.

We think this needs to change. We think that to ensure priority is given to an adult's will and preferences, before any steps are taken to intervene in an adult's life, all practicable steps should be taken to ascertain their will and preferences, and thereafter, any intervention under the AWI Act must be in accordance with the adult's rights, will and preferences.

The exception to this would be if it can be shown that not to follow an adult's will and preferences would be a proportional and necessary means of effectively protecting the full range of the person's rights, freedoms and interests, then steps can be taken.

There will also be circumstances where it is simply not possible to give effect to a person's will and preferences, such as for example an adult wishing to live with their sibling, but the sibling's accommodation is not viable or safe for the adult to live there. In such cases, the expectation would be for time to be spent with the adult to devise an acceptable alternative.

[8] Three Jurisdictions report p 1

Support for decision making

In addition to this change, we think that there needs to be a greater emphasis on support given to an adult to enable them to make their own decisions, before any steps are taken to intervene in the adult's life.

Generally, capacity laws are based on whether a person has the capacity to make decisions or not. The law in Scotland presumes that adults are capable of making personal decisions for themselves and managing their own affairs. When assessing capacity, evidence of the adult's ability to understand any potential risks, and a consistency in this understanding, is considered.

The UNCRPD has spurred us to consider how states might respond differently to disability rights. Central to this is Article 12 which asserts the right of disabled people to equal recognition before the law and requires that states take appropriate measures to provide people with disabilities with the support they require to exercise their legal capacity.

The SMHLR stated that the current framework in mental health and incapacity law in Scotland focuses mainly on protecting individuals with mental disorder from unnecessary intrusions in their life. The final report said that this needs to change and a fundamental part of that change is the development of a comprehensive regime of supported decision making which should apply in all situations. Individuals affected by mental health and capacity law have the same rights as anyone else to make decisions about their lives. And any support required to enable them to do so should be provided.

A priority of the Scottish Government Mental Health and Capacity Reform Programme is to help people voice their opinions through supported decision-making practices. The programme is committed to reviewing existing practices, working with partners to assess effective Supported Decision Making practices. From this baseline decisions will be made on the necessary next steps.

We consider that this shift in approach needs to be fully embedded in the AWI Act. We have been looking at other jurisdictions for examples of good practice.

The Mental Capacity Act (Northern Ireland) 2016 has been praised for its approach. It provides in its principles that:

'the person is not to be treated as unable to make a decision for himself or herself about the matter unless all practicable help and support to enable the person to make decisions about the matter have been given without success.'[9]

We think that a similar condition should be applied to actions under the AWI Act to ensure that interventions only take place when options for supported decision making have been exhausted.

[9] Section 1 (4) of the Mental Capacity Act (Northern Ireland) 2016.)

We suggest that the principles should be amended to provide that prior to any intervention in the affairs of an adult, all practicable help and support to enable the adult to make their own decisions about matters should have been given and shown to have been given without success.

These principles should have priority over all other principles of the AWI Act to ensure that supporting the adult to make decisions, and ascertaining the will and preference of the adult and following those is the priority in considering any intervention in an adult's life. And that not respecting the will and preference is only possible in specified circumstances.

These changes should ensure that the wishes and feelings of the adult, now referred to as will and preferences, are always front and centre of actions under the AWI Act.

However, in order to ensure that there is a consistent approach across the country on the provision of support for adults, and the methods to be used in obtaining the views of incapable adults, there will require to be a comprehensive training scheme for practitioners, and guidance contained in codes of practice.

In addition, guidance, training and support will be required for family members and others who take on the roles of attorneys and guardians.

Over the summer we will be undertaking work to establish a baseline for supported decision making across Scotland at present and we will use this to draft a model for training and support, in conjunction with people who have experience in this area, be it as users of the legislation, carers of those who come within the legislation or practitioners.

How can we ensure the principles are followed?

The principles will only have effect if they are followed by everyone who uses the AWI Act.

At present, training for practitioners points out the need to follow the principles, as does the codes of practice[10]. Sheriffs are expected to consider how the principles have been followed when considering what decisions should be made in respect of the adult. The Office of the Public Guardian (OPG) will ask financial guardians if they have been following the principles and practitioners are expected to reflect in their reports how the principles have been adhered to.

Going forward, with the proposed change in the principles, the requirement to provide support for the adult to make their own decisions before considering an intervention, and the requirement to ascertain and follow an adult's will and preferences will mean that there will be an obligation on anyone seeking an

[10] Adults with incapacity: code of practice for local authorities

intervention under the AWI Act to show how they have adhered to these, as well as the existing principles.

We intend for this to be set out in training. In addition, reports that may require to be prepared for interventions such as guardianship, will require to set out the steps the writer of the report has taken to ensure the principles have been followed. More detail on this is provided in later chapters in this consultation.

It may be considered however that more steps are needed to ensure the principles are followed, and we would be grateful for views as to what additional steps could be put in place to make certain the principles of the AWI Act are followed by any person acting under legislation in accordance with section 1 of the AWI Act.

Questions

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?

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 ?

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?

4. Do you agree that the principles should be amended to provide that all support to enable a person to make their own decisions should be given, and shown to have been unsuccessful, before interventions can be made under the AWI Act?

5. Do you agree that these principles should have precedence over the rest of the principles in the AWI Act?

6. Do you have any suggestions for additional steps that could be put in place to ensure the principles of the AWI Act are followed in relation to any intervention under the Act?

Proposed Terminology changes

Throughout the AWI Act distinction is made between an adult's property and financial affairs and an adult's personal welfare (including healthcare matters). However, the way this distinction is made is different for powers of attorney and guardianship orders.

Under Part 2 of the AWI Act, a power of attorney that relates only to financial matters is known as a “continuing attorney”. This causes confusion and requires repeated explanation to members of the public.

Under Part 6 of the AWI Act a guardianship order can be granted for the protection of the property, financial affairs or personal welfare of the adult.

We consider that there should be easily understood descriptors of the role an attorney or guardian holds. We think these should be the same for both roles.

We recommend changing the term ‘continuing attorney’ to ‘financial attorney’.

A guardian should continue to be known as a guardian with financial, property and / or welfare powers depending on the authority granted to them by the sheriff.

Questions

7. Do you agree with the change of name for attorneys with financial authority only? Please add any comments you have around this.

Sheriff’s power of directions

Section 3(3) of the AWI Act currently provides for the sheriff, on application by any person claiming an interest in the property, financial affairs or personal welfare of an adult to give directions to any person exercising functions conferred by the AWI Act or functions of a like nature conferred by the law of any country.

This is an incredibly useful power, but we consider it needs expanding in two ways.

First we think that the sheriff should be able to give directions to people formerly exercising functions, so that a former attorney or guardian for example could be ordered to provide information. This will ensure greater transparency between individuals currently and formerly exercising functions under the AWI Act and will provide further protection for the adult.

Second, we think that the power under section 3(3) should be extended to a discretionary power to give directions to anyone where that is appropriate for the proper operation of provisions of the AWI Act.

This would provide a route for attorneys and guardians to, for example, request the sheriff to direct a pension provider to transfer payments into an appropriate account. The inability to do something like this at present can cause a great deal of distress for persons acting under the AWI Act and can often mean the adult is not receiving the funds they should.

Authority of the Public Guardian

Section 6(2)(c) of the AWI Act gives the OPG the authority to receive and investigate any complaints regarding the exercise of functions relating to the property or financial affairs of an adult made in relation to continuing (financial) attorneys, intromissions with funds, guardians or persons authorised under intervention orders.

However, the OPG is not allowed to investigate any matters or concerns in relation to a deceased adult. The AWI Act currently only provides official status for the OPG to ensure the estate of an adult with incapacity is protected for the benefit of the adult. The OPG has said that a discretionary power to continue investigations after the adult has died would be very useful. This would minimise the risk of misappropriation of funds in an adult's estate. There is also the consideration of other adults who may be at risk if the OPG is not permitted to continue an investigation after the death of the adult.

We agree with the views of the OPG and propose that section 6(2)(c) be amended to enable an investigation carried out by the OPG, if appropriate, to be continued after the death of the adult, so long as the investigation has started before the adult died.

Questions

8. Do you agree with our proposals to extend the power of direction of the sheriff?

9. Do you agree with our proposal to amend the powers of investigation of the OPG to enable, where appropriate, an investigation to be continued after the death of the adult?

Investigations into cases under the AWI Act

How the process for AWI cases currently works

Presently OPG investigate financial concerns where the adult lacks capacity. This can be where the adult is subject to provisions of the AWI Act, such as where a continuing (financial) power of attorney, a guardianship or intervention order with property and/or financial powers, or authorisation to access funds under Part 3 are in place. OPG can also investigate where the adult lacks capacity and there are no provisions under the AWI Act in place.

The local authority has a duty to investigate cases under the AWI Act if there is a risk to the personal welfare of an adult[11]. The local authority also has a duty in the AWI

[11] S.10 (1)(c) and s.10 (1)(d) AWI

Act to consult the OPG and the Mental Welfare Commission (MWC) on cases where there appears to be a common interest[12] .

The local authority also has a duty to make inquiries under the Adult Support and Protection (Scotland) Act 2007 (ASP Act)[13]. This is if it knows or believes that the person is an adult at risk, and that it might need to intervene in order to protect the person's well-being, property or financial affairs. An adult at risk in this case can include an adult lacking capacity as well as an adult with capacity but who is otherwise vulnerable as described in section 3 of the ASP Act[14].

Section 3 (1) of the ASP Act defines an 'adult at risk' as someone who meets all of the following three criteria (commonly known as the three-point test):

- That they are unable to safeguard their own well-being, property, rights or other interests.
- That they are at risk of harm; and
- That because they are affected by disability, mental disorder, illness or physical or mental infirmity they are more vulnerable to being harmed than adults who are not so affected.

The three criteria above make no specific reference to capacity, although a lack of capacity is a factor in the third criteria.

The ASP Act places a duty on the MWC, the OPG, local authorities, the Police and other bodies to make a referral and co-operate with each other if they know or believe that a person is an adult at risk of harm and that action needs to be taken to protect them from harm[15].

The OPG, when they have information that someone may be misusing financial powers in relation to an adult lacking capacity, report the facts and circumstances of the case to the local authority (i.e. make an adult protection referral under section 5 of the ASP Act). In many cases anecdotal evidence from Health and Social Care Partnerships has shown that where there are reports of financial concerns made to local authorities then as ASP referrals from the OPG, there are usually also concerns relating to welfare matters.

The local authority normally investigates welfare and financial matters using powers under the ASP Act and uses appropriate powers to safeguard adults, including when capacity may be unclear. Section 4 of the ASP Act places a duty on councils to make enquiries about an adult's well-being, property or financial affairs if the council knows or believes that the adult is at risk and the council may have to intervene in order to protect the adult's well-being, property or financial affairs.

Under the AWI Act the local authority have a function to investigate complaints about the exercise of functions relating to the personal welfare of an incapable adult in

[12] S.10 (1) (b) AWI
[13] S.4 ASP
[14] S.3 ASP
[15] S.5 ASP

relation to welfare attorneys, guardians, persons authorised under intervention orders, or any circumstances where the personal welfare of the adult seems to them to be at risk. The AWI Code of Practice for local authorities[16] also requires that a local authority should inform the MWC of the outcome of all welfare investigations.

If, following an investigation, the local authority decides that no further action is required, this should also be reported to the MWC. If the complaint was as a result of a complaint by a third party, they too should be advised of the result. If the MWC are not satisfied with the local authority's investigation into a complaint relating to the functions of attorneys, guardians and interveners under section 10(1)(c) of the AWI Act, the MWC can themselves investigate that complaint[17].

Criticism of the investigatory process

The purpose of any investigation under the AWI Act is to establish if any action requires to be taken to safeguard the personal welfare or property and financial affairs of the adult. There are currently statutory duties and responsibilities around the reporting of concerns for the differing agencies.

The investigatory process for AWI cases has been criticised both in the 2018 consultation and the SMHLR. From this work came the general consensus that the investigation process needed to be more unified across welfare and financial matters. It was felt each of the organisations who have statutory responsibilities to receive and investigate complaints were working independently. It wasn't always clear who the first point of contact should be for cases of common interest and there was no clearly specified escalation process for these cases.

The recent SMHLR set out a recommendation on improving the investigation framework within the AWI Act. It stated that at present there was no clear investigation structure with local authorities carrying out social work functions, Police, the MWC and OPG who are all working independently. It recommended[18] that a comprehensive investigatory framework should be developed with OPG, local authorities, the MWC and Police Scotland and full and equal participation with persons with lived experience including unpaid carers.

Some of the stakeholder views expressed during the SMHLR indicated a need for a clear pathway for investigations, including possible outcomes, which is well communicated to all who may be taking part at every stage, so as to reduce worry and uncertainty about the process. Other views expressed were that the investigation structure of Power of Attorney (POA) was not clear as they did not know who to report their concerns to.

We agree with the SMHLR that there needs to be clearer communication between each of the agencies and agreement made on the investigation pathway for cases of common concern. First contact should be clearly specified, and the escalation

[16] Adults with incapacity: code of practice for local authorities
[17] S.9(1)(d) AWI
[18] SMHLR

process marked out. It needs simplified and perhaps directed through one body and there needs to be more accountability.

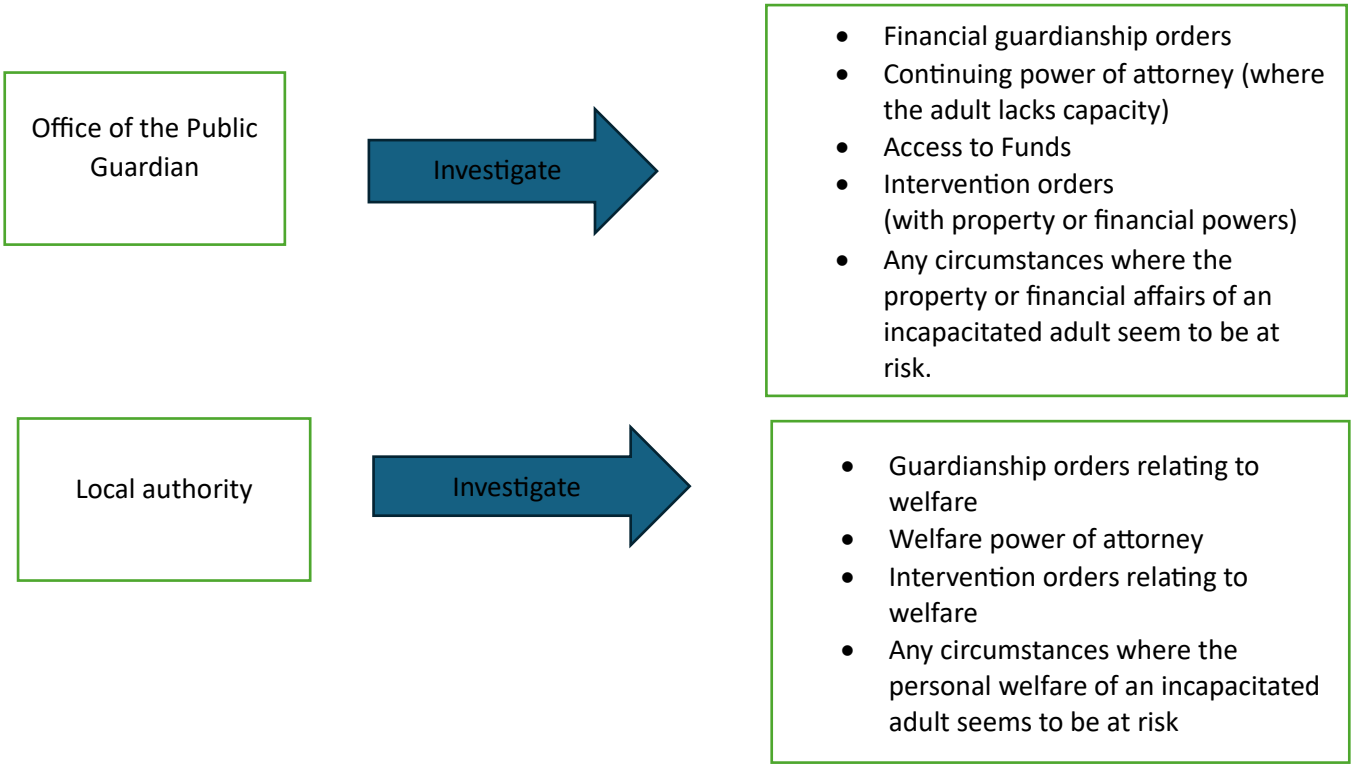
Splitting investigatory responsibilities of the property and financial affairs of adults lacking capacity between the OPG and local authority.

We are proposing that we split the investigatory responsibilities between the OPG and local authority. OPG would retain the investigatory function for the areas it actively supervises and where the adult already lacks capacity. This will cover financial guardianship orders, financial intervention orders and ATF (Part 3).

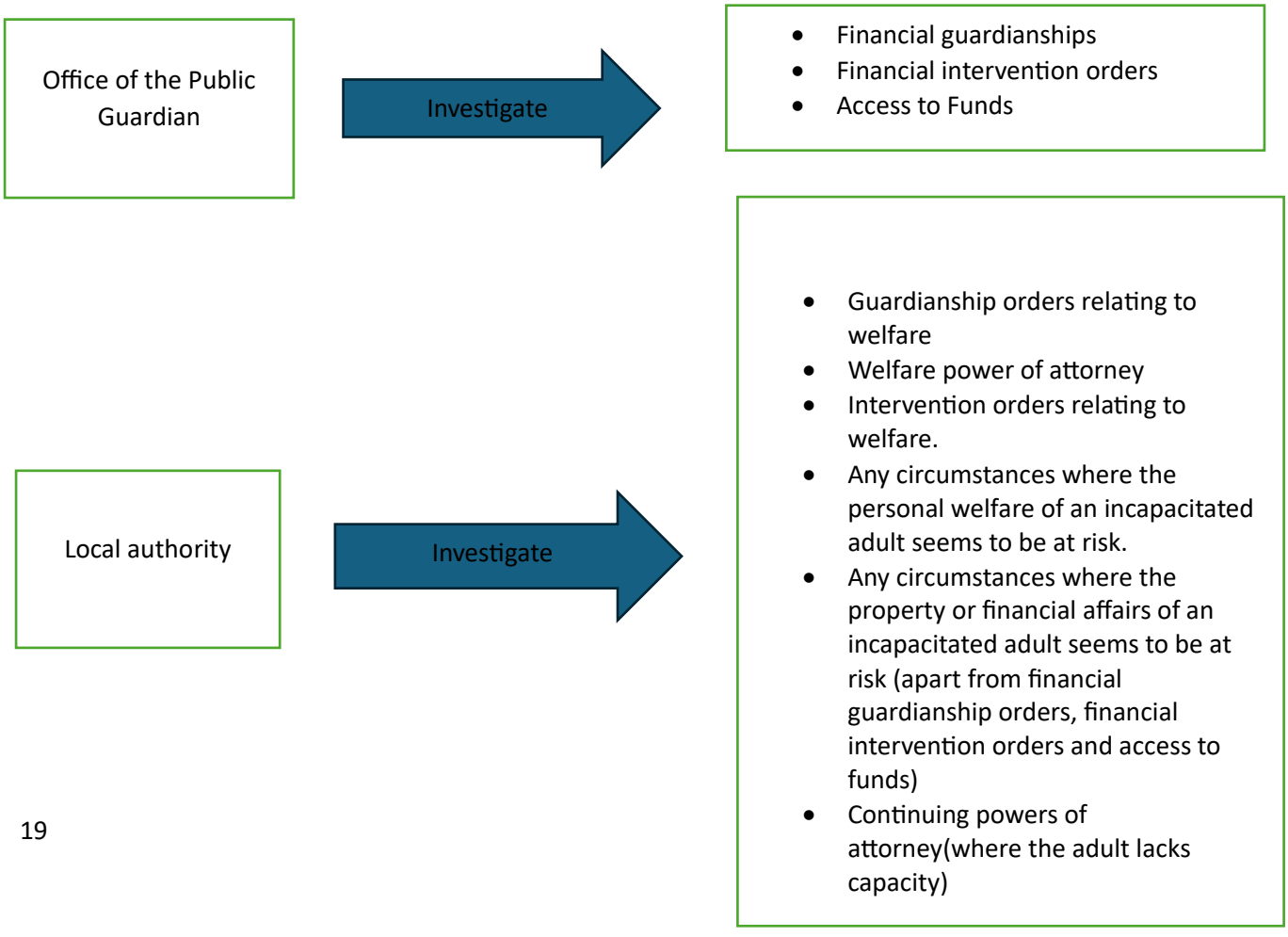
OPG would not have an investigative role in continuing powers of attorney. The local authority as part of its adult support and protection functions would take responsibility for cases where there is a continuing power of attorney or where the adult lacks capacity and there is no order in place under the AWI Act. These are cases where the adult has fluctuating capacity or where there are concerns about capacity or where incapacity has yet to be determined and there is most chance of duplication of effort between OPG and local authorities.

The current process v the proposed process is summarised by the flowchart below:

Current investigation process for AWI cases



Proposed new investigation process for AWI cases



The investigatory powers would be clearer because we are proposing that OPG investigate financial guardianships, ATF and financial intervention orders. However we know that when there is financial abuse it often comes hand in hand with welfare abuse and vice versa. We anticipate that OPG will require to make an adult support and protection referral to the local authority, adhering to their responsibilities under section 5 of the ASP Act (noting that the OPG have duties of cooperation under section 5). The referral will confirm that it is taking forward a property and finance investigation under guardianships, ATF and intervention orders so that the local authority can check the welfare aspects in relation to the adult concerned.

The reason for the proposed structural changes is to provide greater clarity for those reporting concerns so they are clear on the most appropriate agency to contact in the first instance. There would be clearly defined responsibilities and there is the opportunity to reduce duplication of effort and for the respective agencies to develop their expertise.

In a practical sense, difficulties can arise when Council Officers have to complete complex financial investigations, often described as a “forensic accounting task”. Social work practitioners are not trained to undertake these types of financial audits however their evidence through ASP inquiries with investigative actions can be relied upon. These inquiries are time consuming and complex, by their nature. With the changes we are proposing the local authority would have fewer cases like this but would retain the expertise in the area of welfare.

In the course of any investigation, by either the OPG or the local authority, it may be suspected that an offence has been committed under the AWI or ASP Acts. If so a report should be made to the police. The duty to cooperate includes the ability to share information under section 5 of the ASP Act and we do not intend on changing this.

Information sharing between the OPG, the MWC and the local authority is also covered under section 12(2) of the AWI Act which states: For the purposes of any investigation mentioned in subsection (1), the OPG, the MWC and a local authority shall provide each other with such information and assistance as may be necessary to facilitate the investigation.

We anticipate that the proposed changes would promote more joint working between the OPG and the local authority as a direct consequence of the more proactive role they would be undertaking. It would therefore improve the reporting of concerns made to them under section 12 of the AWI Act. The duties under section 5 of the ASP Act would still remain the same and this would include having a data sharing agreement about any cases of interest.

With the proposed changes there would still need to be a clear need for information sharing and communication to be maintained throughout any investigatory process and clear guidance accompanying any statutory changes. Local authorities would require to be satisfied as to the processes and procedures in those situations where the OPG would be the lead investigatory body. This would ensure that there is

confidence in the process and would mitigate the need for a parallel process under ASP duties where this might otherwise be required.

Evidence that information is being appropriately shared as investigations progress and outcomes are identified would give ensure greater confidence in the processes. Governance and monitoring arrangements would require to be developed in order to give assurance that investigations are proceeding as intended and that outcomes are shared, and any additional interventions required are actioned timeously.

The above proposal would delineate which professional body is the identified organisation to lead these investigations and prevent resources from being duplicated in the same case, whilst maintaining information sharing. It would also make it clearer where responsibility lies for investigation of cases.

Questions

10. Do you agree that the investigatory responsibility between OPG and local authority should be split in the manner outlined above?

11. Will these changes provide greater clarity on the investigatory functions of OPG and local authority?

12. Will this new structure improve the reporting of concerns?

PART 2 - POWERS OF ATTORNEY

How the law presently works

Part 2 of the AWI Act allows anyone to plan their future by giving specific powers to someone they trust to make decisions or take decisions on their behalf. This is known as making a power of attorney. The person who makes the power of attorney is known as the granter and the person appointed is known as the attorney. The granter can only make a power of attorney when they have capacity to understand what it means to grant these powers.

Powers of attorney are powerful and useful instruments that allow a granter to retain control over aspects of their lives, in circumstances where they might not otherwise be able to make decisions or take actions. This ensures that the granter has the opportunity to make provision for a future where they may no longer have the mental capacity to understand what is happening to them. If they have fluctuating capacity a power of attorney allows them to still make autonomous decisions about the things they care about.

The powers granted can deal with financial (called a continuing attorney) or welfare matters (welfare power of attorney). A continuing power of attorney[19](often known as financial power of attorney, see Part One) can be used as soon as it is registered with the OPG and continue to be used once the granter has incapacity. A welfare power of attorney[20] allows the attorney to manage the granter's personal welfare or health matters and can only be used once the granter has lost the capacity to make these decisions. A power of attorney document may set out either continuing powers, welfare powers or a combination of both. An attorney can be appointed to deal with financial and welfare matters or different people.

The process of creating powers of attorney and drawing up the relevant documents usually involves a solicitor, but it can be done without a solicitor. The power of attorney must be in writing and if it is to begin in the event of the granter's incapacity then the granter must have a statement confirming that the granter has considered how their incapacity is to be determined. The power of attorney document must also include a certificate from a solicitor, member of the Faculty of Advocates or a medical practitioner stating that they have interviewed the granter before signing the power of attorney document. This is to make sure they are aware of the powers they are granting and the effect of what they are doing, and they are not under any undue influence. The power of attorney can only be used once it has been registered with the OPG.

Attorneys are not routinely supervised under the AWI Act but continuing and welfare attorneys are obliged to keep records and receipts whilst undertaking their duties. Anyone with an interest in the property, financial affairs or personal welfare of the granter of a power of attorney can notify the local authority (under our new

[19] S15 AWI Act
[20] S16 AWI Act.

proposals) of any concerns they have. Where there are concerns about an attorney's decisions relating to the adult's welfare, the local authority has a duty to investigate any complaint about how the welfare attorney is exercising their powers, or investigate any circumstances where the adult's welfare is at risk[21]. We are proposing that the local authority can investigate financial matters relating to the conduct of a continuing attorney.

Any interested party or the local authority can apply to the Sheriff where there are concerns about how certain financial or welfare powers are being exercised by an attorney[22]. The Sheriff has authority to remove some of the attorney's power or require the attorney to be supervised [23].

Summary of changes previously consulted on that we are taking forward

Generally the current system of granting a power of attorney works well, however there have been longstanding views that certain aspects need improving and updating. The SMHLR built upon the 2018 AWI consultation[24] and set out a series of recommendations to address these concerns. We have considered these and previous stakeholder engagement, consultation responses and will be taking forward changes to:

- Clarify when a power of attorney comes into effect and the attorney can start using their powers. Sections 15(3)(ba) and 16(3)(ba) of the AWI Act which set out that the granter has considered how incapacity can be determined are vague and open to interpretation. It is essential that attorneys understand when they can start acting and how to determine capacity .The current situation can lead to confusion, with attorneys acting upon their powers too early and, in extreme cases, an abuse of power. We propose changes so that a power of attorney document contains clear instructions on how the granter wishes their incapacity to be determined before a power comes into effect.

- Clarify whether a welfare attorney may authorise a deprivation of liberty (DOL). Part 7 of this consultation provides further detail on this.

  In addition to these proposed changes to the AWI Act, we are developing work in the following areas:

- We will be working with other agencies in considering different ways in which the cost of a power of attorney may be eased.

- Support training for professionals (for example, care workers, support workers or health care workers) who may need to support adults with incapacity in

[21] S10 of AWI Act.
[22] S3 of AWI Act
[23] S20 of AWI Act
[24] Adults with Incapacity Reform - Scottish Government consultations - Citizen Space

their work. We wish to ensure that professionals understand the different options available under the AWI Act for taking decisions relating to incapable adults so that these different options, including a power of attorney, are able to be used effectively and correctly. For example, we know that there are some cases where an attorney has not been able to use the powers given to them due to a misunderstanding about the nature and use of a power of attorney. That is why part of our work will be ensuring that professionals understand better when and how these powers can be used for the benefit of the person.

- Increase promotion of taking out a power of attorney. With the prevalence of dementia increasing and our population ageing, power of attorney documents become ever more important in ensuring that people can continue to live the lives they want to. We will increase publicity and awareness for all age groups including the younger demographic and backgrounds. Part of this will include dispelling myths and misunderstandings about powers of attorney.

New proposals for change

The following paragraphs in this part set out new proposals for change around the use of powers of attorney.

Mandatory training, support and guidance for attorneys.

Many attorneys are unaware of the obligations under the AWI Act and what their requirements are in fulfilling the role. In the SMHLR [25] it was felt that attorneys receive minimal support and guidance and are not always aware of where to go to receive information. We propose introducing mandatory training for attorneys so that they understand of the requirements of the role and where they can get support in carrying out the role. This is in line with recommendation 13.4 of the SMHLR.

We propose that when attorneys are appointed that they are obliged to undergo a mandatory short introductory training course. This will educate them on their responsibilities, ensure that they understand how the principles of the AWI Act work and enable them to fulfil the duties of the role.

We also want to ensure that attorneys understand the person centred approach of supported decision making and they are familiar with the principles of this. We want them to be able to provide support to granters to assist them to come to a decision that puts their will and preferences at the centre of any decision.

We are envisaging a short, web based presentation easily accessible to attorneys, with clear information on the role of an attorney and where additional help can be found. In checking the attorney's willingness to act as such, the OPG will check if the

[25] Chapter 13 SMHLR

prospective attorney has seen this presentation prior to agreeing to take on the role, and if not, will require the attorney to do so prior to registering a power of attorney.

This work will also develop guidance and training for granters so they are aware of the consequences of granting powers and the safeguards in place to ensure attorneys act appropriately.

Enhancing the safeguards around power of attorney

The OPG has a range of functions under the AWI Act. It is responsible for registering powers of attorney and maintaining a Public register of all continuing and welfare continuing and welfare power of attorneys. It also supervises the actions of those appointed in terms of the AWI Act to manage the property and financial affairs of adults who lack the capacity to carry out these functions for themselves and provided advice and support.

We propose giving OPG additional powers to increase the safeguards when registering a power of attorney. Before any continuing or welfare power of attorney can be used it must be registered with the OPG in Scotland. Section 19 of the AWI Act sets out the process that OPG need to follow to register continuing or welfare power of attorneys. This allows the information about the power of attorney to be recorded in public registers by OPG, so that the information about the powers is openly available on the public register.

Currently if there is a dispute around the possible capacity of the granter of a power of attorney OPG have no discretion to refuse to register the case. Competency issues may arise if the evidence presented on capacity is not clear because the sender has submitted capacity evidence but they may be in dispute with a third person who has also submitted their own evidence. In this case there is contradictory evidence presented about capacity issues. and further evidence is needed to clarify and decide the matter.

At present, if there is a properly registrable power of attorney and there is a query about capacity, the OPG pauses registration and submits an application for directions under section 3 of the Act to the Sheriff. This process can average 14 weeks and causes a delay in the process as well as additional expense.

We propose that there should be provision for the OPG to refuse to register a power of attorney if there is a dispute about capacity. OPG should be able to call for additional capacity reports if there is a reasonable cause. This would allow OPG to pause registration and resolve the issue of capacity/incapacity administratively. If OPG refuse to register the power of attorney, then either party will be able to seek directions from the Sheriff themselves for the matter to be determined by the court.

This approach would seem sensible as it would build in greater discretion in the legislation as at the moment OPG have no power under the legislation to refuse to register. This would allow OPG to satisfy themselves if for example there were questions about capacity. It is proposed that section 19(2) is amended to reflect this change.

The same should apply to registration of a revocation notice under section 22A. Revocation means that the granter of the power of attorney can cancel the power of attorney if certain conditions are met and the OPG has to update the register with that information. This shows if power of attorney is active or not.

Section 22A of the AWI Act sets out the process of revocation of a continuing or welfare power of attorney. This needs to be in a written document and must include evidence that the granter was not acting under undue influence and understood the effect of the revocation. We propose that the same changes should apply to a revocation notice as above for registration of powers of attorney. We propose that there needs to be discretion built into the legislation that allows OPG to refuse to register the revocation notice if there is a dispute about the evidence. The OPG should be able to request further information or reports to satisfy themselves that the evidence meets the requirements of the legislation. This means that the changes would allow OPG to pause registration of revocation and refer it to the court for the Sheriff to make the decision if they have any doubts about capacity.

This provides consistency with the process we propose above for section 19 of the AWI Act and allows OPG to undertake their requisite checks by asking for further information. The proposed changes should make the registration more efficient as it saves time in the process and enhances the safeguards around power of attorney.

Investigatory framework

We propose changing the investigatory process that OPG currently undertake**.** OPG currently have certain statutory powers to investigate an attorney to safeguard financial matters only. We have earlier proposed that the local authority carry out these functions for attorneys. Section 12(1) of the AWI Act sets out that after an investigation OPG may take such steps, including making an application to the sheriff, to safeguard the property and financial affairs of the adult. This may occur if there has been evidence of financial irregularity or bank statements, or other financial information is missing.

The current process is that OPG would need to make an application to the Sheriff under section 20. This sets out that anyone claiming an interest in the property or financial affairs of the adult may make an application to the sheriff under section 20(2)(a) of the AWI Act to request that the Sheriff rules that the continuing attorney be subject to the supervision of OPG. The Sheriff specifies the nature and extent of this supervision.

We propose that the AWI Act is amended to allow OPG to put an attorney under supervision (subject to an appeal to the sheriff), to give directions to an attorney, and to suspend an attorney from acting pending a decision by the sheriff under section 20. OPG can determine the length of time of the supervision. Any decision of the OPG will carry a right of appeal to the Sheriff court.

Giving OPG the power to determine whether they need to supervise an attorney, give directions or suspend an attorney on cause shown after an investigation (by the

local authority under our new proposal) rather than needing a court order, creates an immediate safeguard. It also gives the OPG additional powers to deal with any financial irregularities discovered as a result of an investigation by the local authority under our new proposals. We consider that OPG have the expertise and experience to decide such matters. And this change should save court time and strengthen the safeguards around financial powers of attorney.

Increasing accessibility of powers of attorney.

We know from the SMHLR[26] that widening accessibility of power of attorney is important to increase the uptake of power of attorney documents. We propose to increase the class of persons that are allowed to certify a granter's capacity in a power of attorney document**.**

Sections 15(3)(c) and 16(3)(c) of the AWI Act sets out the process that is required to certify both a continuing and a welfare power of attorney. This states that the power of attorney must include a certificate in a prescribed format, confirming that the granter understands its nature and extent. The certificate can only be completed by a practising solicitor who is registered to practice law in Scotland, a UK registered and licensed medical practitioner or a practising member of the Faculty of Advocates as set out in the certification regulations.[27]

The certification process involves the solicitor, or other prescribed person interviewing the granter immediately before the granter signing the document. They must certify that the granter understood what they were signing. If the granter appears to be failing in capacity, recent medical evidence might be requested. The solicitor or other person acting must also certify they have no reason to believe that pressure or undue influence has been put upon the granter, especially if capacity is declining and they are vulnerable.

To increase accessibility, we propose that the certification regulations are amended to add clinical psychologists to the list of professionals who can complete a certificate confirming the granter has capacity to grant a power of attorney. Clinical Psychologists are mental health professionals who have extensive training in the field of mental disorders and have the knowledge and expertise to undertake this role.

The Law Society of Scotland operates an accredited paralegal status[28]. Accredited paralegals in Scotland carry out many of the same functions as solicitors and it is suggested that the training they undergo would give them the skills to certify a granter's capacity for powers of attorney as they work closely under the supervision of a Scottish solicitor, either in private practice or in-house.

[26] 13.2.2 Scott Review
[27] The Adults with Incapacity (Certificates in Relation to Powers of Attorney) (Scotland) Regulations 2008
[28] The Law Society Accredited Paralegals

We therefore propose also amending the certification regulations to add accredited paralegals to the list of professionals who can complete a certificate confirming the granter has capacity to grant a power of attorney.

Broadening powers of Public Guardian to order compliance with demands in relation to property and financial affairs of the adult.

At present section 64(7) of the AWI Act states:

"(7)The guardian shall comply with any order or demand made by the Public Guardian in relation to the property or financial affairs of the adult in so far as so complying would be within the scope of his authority; and where the guardian fails to do so the sheriff may, on the application of the Public Guardian, make an order to the like effect as the order or demand made by the Public Guardian, and the sheriff's decision shall be final."

We think that rather than restrict the Public Guardian's powers in this area to guardians, they should be extended to attorneys under a power of attorney, interveners and withdrawers (under Part 3). This will assist the Public Guardian in her supervisory duties in respect of these areas and provide greater safeguards for the adult.

We also think the Public Guardian should have wider powers to suspend powers granted to a proxy under section 12 of the AWI Act whilst an investigation is ongoing. Section 12 already allows the Public Guardian, MWC or local authority to take such steps, including an application to the sheriff, which seem necessary to safeguard the property, financial affairs or personal welfare of the adult. The power to suspend powers would be an additional safeguarding option, where even though the investigation is still on-going the Public Guardian is satisfied in the interim that the proxy should not be able to intromit with the estate.

For instance, at the moment the Public Guardian can freeze bank accounts and benefits/pension payments in, but that may still leave other powers the proxy can utilise, for example taking out finance, signing legal agreements and cashing in policies. It is likely that the power would not be used often and practically could only be used if the adult was not living in the community and care or emergency costs were covered by the local authority. This would be appealable to the sheriff.

We are also interested in your views on whether the power to suspend powers should also be available to the local authority and the MWC as part of their investigations.

Questions

13. Do you agree with the proposals for training for attorneys?

14. Do you agree that OPG should be given power to call for capacity evidence and defer registration of a power of attorney where there is dispute about the possible competency of a power of attorney document?

15. Do you agree that OPG should be able to request further information on capacity evidence to satisfy themselves that the revocation process has been properly met?

16. Do you agree that OPG should be given the power to determine whether they need to supervise an attorney, give directions or suspend an attorney on cause shown after an investigation rather than needing a court order?

17. Should we extend the class of persons that can certify a granter's capacity in a power of attorney?

18. Do you agree that a paralegal should be able to certify a granter's capacity in a power of attorney?

19. Do you agree that a clinical psychologist should be able to certify a granter's capacity in a power of attorney?

20. Which other professionals can certify a granter's capacity in a power of attorney?

21. Do you agree that attorneys, interveners and withdrawers (under Part 3) should have to comply with an order or demand made by OPG in relation to property and financial affairs in the same way as guardians?

Broadening powers of the Public Guardian

22. Do you agree that the Public Guardian should have broader powers to suspend powers granted to a proxy under the AWI Act whilst an investigation is undertaken into property and financial affairs?

23. Do you agree that the MWC and local authority should have broader powers to suspend powers granted to a proxy under the AWI Act whilst they undertake an investigation into welfare affairs?

PART 3
ACCESS TO FUNDS (ATF)

Introduction

Part 3 of the AWI Act relates to the ATF scheme run by the OPG.

This part was intended to be a simple way of managing an adult's financial affairs. It allows an individual supporting an incapable adult to obtain authority from the Public Guardian to withdraw money from the adult's bank or building society account to meet household and other necessary expenditure for the adult.

Such a scheme is far less onerous than guardianship and we consider there remains a need for something like this. However the present ATF scheme has not been widely used. Only around 200 applications a year are received, and the way the present scheme is set up is viewed by some as complex, overly bureaucratic and inflexible, raising barriers to more people using the scheme.

How the scheme works at present:

An application is made by the applicant to OPG to transfer a set amount of funds from the adult's current account to a new 'designated' account. It is the 'designated' account that the withdrawer can use to remove funds to spend on or on behalf of the adult.

A medical certificate and a statement from a person who has known the applicant for at least a year is part of the application and currently a fee of £97 is required. Once authorised the withdrawer has access to the funds in the designated account. The withdrawer uses these funds for direct debits and day to day expenditure of the adult, such as care home fees. This has to be estimated for the month and the amounts required are laid out in the application form.

On receipt of the application OPG will check it has been completed correctly and the correct fee is present. There is a large number of initial rejections such as no or incomplete medical forms, no supporting evidence for the requests made or no or incorrect fee. Once satisfied the application is competent, OPG will intimate the application on the adult and other persons listed in the AWI Act. An application must not be granted without the OPG affording any person who wishes to object an opportunity to make representations. Where the OPG proposes to refuse the application the applicant must get an opportunity to make representations if the applicant objects to this[29]. In practice, representations can be made in writing, by telephone, in an online meeting (for example Zoom) or in person. OPG will then come to a decision. The Public Guardian can remit an application to the sheriff on her own instance, at the instance of the applicant or at the instance of any person

[29] S.27E

who objects to the granting of the application. Once authorised OPG will add the details to the public register and send a certificate of authority to the withdrawer, which will contain the specific financial amounts in the application form. This can then be presented to the financial institution.

If there are any changes to the amounts requested, a new application has to be made to the OPG. The Public Guardian does not actively supervise withdrawers under the ATF scheme at present. The Public Guardian monitors withdrawers, meaning that a random selection of cases is taken from time to time for checking.

Powers available under The ATF Scheme at present

Authority to provide information about funds.

This application is for a certificate authorising any fundholder to provide the person with such information as the person may reasonably require in order to make a further ATF application.

Authority to open account in adult's name

This application can be made at the same time as the application to access funds and is to open an account where there is not already one suitable for an ATF application. This would be used in cases where it is known the adult has funds or payments that could be accessed via this scheme if such an account was opened.

Authority to intromit with funds

As it stands this requires specific amounts of money (as detailed in the application form) to be transferred from the adult's current account to a new 'designated' account. From this withdrawals can be made for the specific amounts and purposes detailed in the application. The withdrawer can also continue and set up standing orders and direct debits from the adult's current account to pay the adults living expenses. The idea is that this transfer from current account to designated account provides some safeguard for the adult's finances.

Suggestions for change

We don't intend to change the method of application, as described above. We also propose to keep a separate application to find out what funds the adult has, prior to an application to access those funds, if there are any, as described above. What we are suggesting are changes to the main ATF application. This will allow the scheme to have greater flexibility, with the safeguard of OPG supervision.

We are suggesting that, rather than monitor withdrawers under the scheme, the Public Guardian should actively supervise withdrawers. This will mean taking an annual view of the actions of every withdrawer with respect to the adult's finances.

We think this would look similar to the accounting requirements for guardianships[30], albeit with a lighter touch. This gives discretion for the Public Guardian to give directions as to the frequency of accounting periods, dispense with the need for submission of accounts, or require the guardian to do anything in lieu of submitting accounts. It also allows the Public Guardian to prescribe the form of the accounts and prescribe different forms for different cases. Given the limited powers of the withdrawer, it is anticipated that accounting will be of a briefer form than the accounting required in terms of the present guardianship scheme, at the discretion of the Public Guardian. Given the lower level of authority given to a withdrawer, the ATF scheme should remain as at present with no remuneration or reimbursement of outlays for a withdrawer.

At present the scheme is very restrictive, with any changes requiring an application to OPG. We understand that this is for safeguarding reasons, however it has also resulted in the scheme being considered unwieldy and difficult to use. Our proposal is for the scheme to grant proforma powers at the outset for the same functions it already does, without the necessity for additional applications to OPG for additional authority or to change amounts. Safeguarding will be provided by a requirement to estimate the amounts required for each purpose at the outset. This will then be checked by OPG on an annual basis to see that the withdrawer has acted appropriately. This will provide a deterrent and will allow OPG to make enquiries if anything untoward is found.

The AWI Act provides that the application must state the purposes of the proposed intromission with the adult's funds, setting out the specific sums for each purpose[31]. We think the latter half of this statement can be removed, allowing the withdrawer flexibility to change the amounts depending on circumstances. We would expect an indication of each amount still to be given to OPG, with an obligation in the AWI Act to do so, but the inclusion in the AWI Act of 'specific sums' leads to lack of flexibility and a new application being required should amounts change.

In order to make the scheme more usable and flexible our proposal is to remove the requirement for the certificate to reflect the exact finances to be accessed by the withdrawer. These will be to pay for care home fees, holidays, clothing, and other related goods and services for the adult[32] . An estimate of these amounts can be provided to OPG at the time of application, for supervisory purposes, however they will not be reflected in the withdrawal certificate.

At present for instance, if the care home fees went up from £500 to £600 an application for variation of the amount would be required. Under our proposal the withdrawer can amend this amount for withdrawal, or any other amount that corresponds with the powers they have, without a variation application. There will be no specific limits on the amount any sum can be increased. Any transactions will have to be explained when accounting is provided to OPG. As explained above we

[30] Schedule2, sections 7 and 8
[31] s.26(1)(a)
[32] S.24A(2)

think OPG should actively supervise withdrawers and a brief type of annual account, at the discretion of the Public Guardian, should be required.

The certificate will only reflect that the withdrawer has power to set up direct debits and standing orders for specific purposes and the other powers that are available under the scheme. Meaning that if bills go up or down the withdrawer can amend the standing order or payment without another application.

The setting up of a 'designated' account and transfer of funds from the adult's current account to the 'designated' account can be confusing for financial institutions. There is mixed compliance with this, with some institutions providing direct access to the adult's current account. Where institutions do provide access to the adult's current account, these transactions are at present unsupervised. We think access should be provided directly to the adult's current account, the risks associated with which can be offset by Public Guardian supervision. This makes for a clearer, less complicated scheme.

Varying pre-existing arrangements on the adult's account

The AWI Act states[33] that the withdrawal certificate may (amongst other powers[34]) "authorise the continuance or making of arrangements for the regular or occasional payment of funds from the adult's current account for specified purposes (for example: by standing order or direct debit)"

We think this is too restrictive. In order to make any adjustments to any existing arrangements that have been set up on the adult's current account (for instance a standing order or direct debit), the withdrawer would need to apply for a full variation order[35].

The wording is limiting and additionally, needs to grant the withdrawer, via the withdrawal certificate, power to vary any prearrangements on the adults account.

What we think the withdrawal certificate should allow

Therefore we think the withdrawal certificate should allow:

- Authority to open or close an account in the adult's name
- Transfer of funds between the adult's accounts
- The continuance, variance or making of arrangements for the regular or occasional payment of funds from the adult's current account for specified purposes (for example by standing order or direct debit)

[33] s.26A(1)(b)
[34] in s.26A(1)
[35] under section 26F

- The termination of regular or occasional payment of funds from the adult's current account for specified purposes (for example by standing order or direct debit)
- The withdrawal of funds from the current account for specified purposes
- Administration and disbursement of funds for Self-Directed Support

Questions:

24. Do you agree that the powers and specific amounts should be decoupled?

25. Do you agree that the withdrawal certificate should contain standard, proforma powers for the withdrawer to use?

26. Do you agree that access should be given to the adult's current account, rather than setting up a 'designated account'?

Applications where there is a guardian, continuing attorney or intervener with powers relating to the funds in question

The AWI Act states[36] that an application cannot be made in the case of an adult in relation to whom there is a guardian, continuing attorney or intervener with powers relating to the funds in question.

There are cases where an application for ATF may be necessary where there is an intervener or guardian in place in relation to the same funds. For instance interveners may have a power to transfer funds (perhaps from the sale of a house or other asset) into an account that in accordance with the least restrictive intervention principle[37] should be administered under Part 3 of the AWI Act. In order to have a seamless transition, it may be preferable for the application to access funds to be made whilst the intervention order is still operative. The intervention order will fall once the powers in it have been used.

There is also the possibility that a guardianship order is granted but the estate has reduced so that it would be more appropriate to be managed by ATF. That would require an ATF application whilst there was a guardianship order in place in order to ensure there was no gap in protection. Transition from guardianship order to ATF is already provided for in the AWI Act[38]. However the AWI Act itself states that an application for ATF cannot take place whilst a guardianship order for the same funds is in place, rendering the transition provisions inoperable.

[36] s.24B(2)
[37] s.1(3)
[38] S.31E

We think that the provisions preventing ATF applications when there are attorneys with powers over the same funds should remain in place.

Question:

27. Do you agree that in certain circumstances, applications where there is a guardian, or intervener with powers relating to the funds in question should be allowed?

Application when there is already authorisation to intromit with the same funds

The AWI Act states[39] that an application cannot be made to intromit with an adult's funds if a person is already authorised to intromit with the funds of the adult to whom the application relates.

We think the wording "already authorised to intromit" is confusing and rather than refer to applications under this section, could refer to authorisations under other provisions as well, such as DWP appointments. We intend to clarify that a bar to applying under this section only applies if someone already is authorised only under Part 3 of the AWI Act to intromit with the same funds.

Question:

28. Do you agree that we should clarify that a bar to applying under this section only applies if someone is already authorised under Part 3 of the Act to intromit with the same funds?

Account held by fundholder in adult's sole name

The AWI Act states[40] that an application must specify an account held by a fundholder in the adult's sole name which the applicant wishes to use for the purpose of intromitting with the adult's funds.

We have heard that this may limit organisational use of the scheme. There may be occasions where an organisation, for ease of administration, would want to use a single client or corporate account to hold the funds of a number of people. Although these funds wouldn't be in an account in the sole name of the adult, they would be clearly identified as the adult's funds and belonging to the adult.

Question:

29. Does having an account in the adult's sole name limit organisational use of the scheme?

[39] S.25(5)
[40] S.26(1)(b)

Transition to ATF from intervention order

The AWI Act refers[41] to transitions to the ATF scheme from guardianships. Currently there is not an equivalent transition available from intervention orders. Instead, people are encouraged to apply for a guardianship order as it involves less paperwork. However this might not be the least restrictive method according with the principles of the AWI Act.

As it stands a transition to ATF from guardianship requires an application, but it doesn't need a counter signatory and the Public Guardian may disapply the requirement for medical certificate. We propose that the same applies to intervention orders. For instance, in accordance with the least restrictive principle, there could be an intervention order to sell a house, but then authority under the ATF scheme to deal with the proceeds.

Question:

30. Should we add the same transition provisions to intervention orders as there are for guardianships?

Sheriffs to be able to approve ATF if previously a guardianship order has been applied for and ATF is deemed a lesser intervention.

When a guardianship order is applied for through the court, the court rules provide that the application is served on a number of different persons, including the Public Guardian, in order that they can comment on the application or attend a hearing.

The Public Guardian provides comments regularly to the sheriff court on cases. There are often cases where the Public Guardian comments that a financial guardianship is not required and authority via the ATF scheme would be a lesser, more appropriate intervention. Often guardianship orders are granted in these cases.

We think one of the reasons is that if the financial guardianship application was refused, then the applicant would have to begin making an ATF scheme application from the beginning, denying the adult the protection and access to their finances that a financial guardianship could provide at that point.

We think, only in these specific cases, a sheriff should be able to grant authority via the ATF scheme, rather than a financial guardianship order. That would prevent the hiatus in applications creating a lack of protection and access to their finances for the adult. Our proposal, where the powers given in the withdrawal certificate are not bound to specific amounts, would make this possible.

[41] S.31E

Question:

31. Do you agree that sheriffs, under certain circumstances, should be able to grant powers to access funds under our new proposal?

Inclusion of authorised establishments in the ATF scheme

The AWI Act allows 'a body' to apply for ATF. For example, local authorities can apply. However, it excludes authorised establishments within the meaning of section 35(2) from applying. Authorised establishments under section.35(2) are:

- A health service hospital
- An independent hospital or private psychiatric hospital
- A state hospital
- A care home service
- A limited registration service

This is because they are specifically catered for by Part 4 of the AWI Act dealing with management of residents' finances. Part 4 is very little used, as described later and we are proposing that it is removed. On that basis we think that authorised establishments should be allowed to apply under the ATF scheme, along with other organisations.

Question:

32. Do you agree that authorised establishments should be able to apply under the ATF scheme?

Intimation of application

As stated previously, the Scottish Law Commission (the Commission) envisaged ATF as being an application where an individual could obtain authority from the Public Guardian to withdraw the adult's money for the adult's benefit.

To reflect this intimation on interested parties is carried out by OPG. The most recent OPG statistics show that more than twice the number of applications are received from local authorities, or other organisations rather than individuals.

We are therefore suggesting, to share the administrative responsibility for this, that where the applicant is an organisation, they should provide intimation of the application to interested parties. Where the applicant is a lay person, OPG will provide intimation of the application as they do at present. This will reflect practice in the sheriff courts[42].

[42] Statutory Instrument 1999 No. 929 (S. 65), rule 3.16.4(2)

Question:

33. Do you agree we should split intimation of the application between organisations and lay people (OPG)?

PART 4

MANAGEMENT OF RESIDENTS' FINANCES

Part 4 of the AWI Act concerns adults who reside in authorised establishments who lack the capacity to manage their financial affairs. Authorised establishments are defined in the AWI Act as health service hospitals, independent hospitals or private psychiatric hospitals, the state hospital, care home services and limited registration services. Part 4 provides a mechanism for managers of those establishments to manage finances to a limited extent on the adult's behalf. Reports from various healthcare providers indicate limited instances of the application of Part 4 in practice.

To assess the uptake of Part 4 of the AWI Act, we contacted all health boards across Scotland to find out how often and in what circumstances part 4 was used. We received no information to suggest Part 4 was being used at all.

We met with the Care Inspectorate, who are the supervisory body responsible for care homes under Part 4. They advised us that there are no users of Part 4 in the care home sector for a variety of reasons. Using Part 4 to manage the finances of residents who lack capacity is resource-intensive, requiring additional staff training and ongoing monitoring. But care homes do not receive any compensation or reimbursement for these added responsibilities. Care homes see the use of Part 4 as a financial burden rather than a beneficial service to their residents.

Care homes have also said that staff have found Part 4 too complex due to the intricate legal requirements, administrative burdens, and nuanced decision-making processes involved. There is limited capacity to train staff and assessment procedures can be disproportionately time-consuming. Disputes between residents, families, and staff can further complicate implementation. Overall, the complexity often deters care homes from adopting Part 4 for financial management.

Guardianships and intervention orders have often been favoured over Part 4 due to their tailored approach and their familiarity within the legal and healthcare systems. However applying to the Sheriff Court for guardianships and intervention orders can be time consuming and costly. Our proposals for reform of Part 3 of the AWI Act relating to the ATF scheme will allow authorised establishments to apply under that scheme. We think this will allow a more flexible approach to be applied by authorised establishments, with the safeguard of supervision by the OPG.

In response to the above, we propose removing Part 4 from the AWI Act due to its low uptake, complexity, and the availability of alternative mechanisms like ATF, guardianships and intervention orders. This streamlining would simplify decision-making, reduce administrative burdens, and ensure more accessible support for individuals with incapacity.

Questions:

34. Do you support the proposal to remove Part 4 from the AWI Act?

35. Do you think alternative mechanisms like the ATF scheme, guardianships and intervention orders adequately address the financial needs of adults with incapacity living in residential care settings and hospitals?

PART 5

AUTHORITY TO MEDICALLY TREAT ADULTS WITH INCAPACITY

Part 5 of the AWI Act gives authority to treat a person who is incapable of consenting to medical treatment to safeguard or promote their physical or mental health.

Section 47 of the AWI Act allows the medical practitioner (or other specified healthcare professional) who is primarily responsible for the adult's treatment to complete a certificate certifying that in their opinion the adult is incapable of making a decision on the medical treatment in question. Once the medical practitioner or healthcare professional complies with the certification requirements set out in section 47, they then have a general authority to do what is reasonable in the circumstances in relation to medical treatment to safeguard or promote the physical or mental health of the adult.

The certificate provides authority to give treatment but has no specific provision on conveying a patient to hospital. The Commission's report in 2014[43] on Adults with Incapacity had noted that there were concerns whether there was sufficient authority to transport persons to hospital where they lack capacity to agree to that action (paragraph 4.9). However they concluded that conveying a person to hospital could normally be justified under the common law principle of necessity in an emergency and may otherwise be authorised by the fact that a certificate under section 47 gives "authority to do what is reasonable in the circumstances, in relation to the medical treatment in question, to safeguard or promote the physical or mental health of the adult". This could include taking someone to hospital to receive treatment. But conveying someone to hospital for non-urgent care would require an existing s.47 certificate to be in place.

The SMHLR considered the issue of conveying a person to hospital to receive treatment for a physical condition and its views are noted below:

"We generally support as much alignment as possible between mental health and capacity law as possible. However, in relation to conveying people to hospital for treatment for a physical condition, we are not persuaded that the Mental Health Act model can be directly transposed. In many situations it may be GPs, community nurses or paramedics who have to decide, often in a situation of great urgency, whether a person should be admitted to hospital, even if they are too unwell to agree or may be resisting admission.

We propose an adapted s.47 certificate should be used to grant authority to convey a person who appears to be unable to consent to admission. This would record the reasons the person was felt to be unable to consent, why admission was felt to be necessary, and what attempt was made to ascertain the will and preferences of the

[43] Scottish Law Commission Report on Adults with Incapacity October 2014

adult. It would also be important to identify whether the person was simply unable to agree, or actively unwilling to go to hospital. In the latter case in particular, the adult should be supported to challenge their remaining in hospital, if they continue to be unwilling to say. We do not suggest that this would be necessary in cases where a person was unconscious, and there was no indication of any reluctance to be admitted to hospital “

The Scottish Government agrees with the SMHLR that an adapted section 47 certificate should be created to grant authority to convey a person who appears to be unable to consent to admission to hospital. This is for the purpose of receiving physical treatment or diagnostic tests where the adult is unable to make an autonomous decision.

Common law allows medical treatment to be given in an emergency to patients who cannot consent. Under the “principle of necessity” treatment can be given in order to preserve life or for the prevention of serious deterioration in the adult’s medical condition. This would cover adults who are unconscious for a short time when they arrive at Accident and Emergency unit.

This process is not intended to replace that but to capture those adults that are incapacitated under the AWI Act. Where it is clear that a patient falls under the definition of “incapable” either by reason of mental disorder or of physical disability causing inability to communicate that can’t be aided, this process is to be used to convey the patient to hospital and keep them safe in hospital whilst receiving treatment for medical treatment or undergoing tests.

We therefore propose to introduce a new adapted section 47 certificate that would expressly allow a person to be conveyed to hospital and ensure that this process is authorised in law. We agree with the SMHLR that in relation to conveying people to hospital the Mental Health model cannot be directly transposed. The circumstances are different and require a different approach. We suggest:

- Suitable professionals such as GPs, paramedics and community nurses would grant the authority to convey an adult to hospital who could not make an autonomous decision. They are the ones who are most likely to be in contact with the adult when they need admission to hospital.

- The process for authorisation would also involve recording the reasons why the adult should be admitted to hospital for, such as for physical treatment (including needing diagnostic tests), for example and would need to be conveyed to hospital.

- There would be a section in the section 47 certificate where the reasons why the adult was unable to consent would be recorded.

- An important part of this would be recording whether they were unable to agree or actively unwilling to go to hospital.

- Part of the assessment process would involve recording on the section 47 certificate what attempts were made to ascertain the will and preferences of the adult.

- Where practicable, any attorney or guardian including family members should be consulted.

- If the adult still contests their stay in hospital after they have arrived, they should be supported to appeal this.

- There will be a review and renewal of the certificate after 28 days and a limit on this so that the adult does not remain in hospital indefinitely.

Questions

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?

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?

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

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

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

Currently Scots law provides no specific process to authorise measures to prevent a person being treated in hospital for a physical condition from leaving. This gap was identified in the Commission's report on Adults with Incapacity in 2014. In the previous Scottish Government consultation in 2018 [44]AWI proposals for reform there was agreement that an enhanced section 47 certificate process should be developed to provide clarity in this area of law.

[44] Adults with Incapacity Reform - Scottish Government consultations - Citizen Space

The SMHLR considered this as follows:

“In relation to being required to remain in hospital, there was agreement that this is a significant gap in the law which must be closed. It was generally agreed that, where the person is unable to make an autonomous decision to remain in hospital, and there is no-one else who can consent on their behalf, it would be disproportionate to require a DOL order to be sought from a court. But there need to be safeguards against people being made to stay in hospital, potentially against their will, without access to proper review.

There also appears to have been broad support for broadening the section 47 certificate, although there were differing views about whether the 28 day period was appropriate.”

We agree with SMHLR that there is a significant gap in the law that needs to be remedied given the lack of a specific process to authorise measures to prevent a person being treated for a physical condition from leaving hospital, whether temporarily or permanently.

We are proposing that an additional process is required to enable authorisation of any necessary measures to prevent an adult with incapacity from going out of a hospital unaccompanied and that this process should be connected to the process of authorising medical treatment.

Under section 47(4) of the AWI Act the meaning of “medical treatment” is broad enough to include diagnostic tests and procedures. When it is clear that the patient is incapable either by reason of mental disorder or due to a physical disability meaning they cannot communicate and that this can’t be aided, then a process should be used to keep the patient safe whilst undertaking medical treatment in hospital.

Responsibility for certifying that an adult lacks capacity to decide whether or not to stay in hospital should rest with the medical practitioner primarily responsible for the treatment or assessment of the patient. This mirrors the formulation in section 47 of the AWI Act but is more limited than who can grant a section 47 certificate generally. The authority to provide medical treatment under Part 5 does allow for dental treatment and treatment by an ophthalmic optician but we don’t propose to introduce these measures for dental treatment or treatment by ophthalmic optician. We consider it is appropriate to limit the above decision as to capacity to the medical practitioner primarily responsible for that person’s care because in practice a hospital is the place where measures to prevent a patient from going out are most likely to be needed.

We propose the following new measures:

- The lead clinician responsible for authorising the medical treatment or assessment can authorise measures to prevent the adult from leaving the hospital whilst these are undergoing. The lead clinician would record their reasons for this in the enhanced certificate. This could be the consultant to whom a patient is assigned but also any medical practitioner who is for the time being responsible for the treatment of the adult.

- We propose that the lead clinician consults with the patient's family and guardian and attorney wherever it is practicable and reasonable in the circumstances. This is in line with principle 4 of the AWI Act (consultation with relevant others) and similar to section 50 of the AWI Act whereby the medical practitioner has to seek consent to the proposed medical treatment.

- Once consent is provided the patient will be prevented from leaving hospital until the medical treatment or assessments have been concluded and measures are required to keep them safe for physical health reasons.

- A review process of the measures authorising placement in hospital would be embedded in and the clinician in charge of the treatment or assessment would be responsible for setting the time-scale for this.

- As part of the review process, the clinician would need to consider when treatment or assessment is likely to come to an end. Capacity can also fluctuate whilst staying in hospital so the clinician will have a duty to review whether the patient lacks capacity.

- Any guardian or attorney must be consulted during the review process and the measures must be taken to support the patient through this.

- We also propose that the lead clinician can revoke the certificate if the patient recovers and it is no longer necessary.

- We propose a review interval of 28 days. The review process will consider factors set out above and part of this review will involve the clinician applying the general principles of the AWI Act as set out in section 1. The clinician must ensure that measures must likely benefit the adult and the potential benefit cannot be achieved without treatment. The measures must be the least restrictive option in relation to the freedom of the adult, consistent with the purpose of the treatment. Restriction measures can only be renewed up to 3 months before it then needs to be considered by Sheriff court.

- An attorney or guardian, family member, or any person with an interest in the adult's welfare can appeal the treatment and restriction measures at any time and make an application to the Sheriff court. We suggest that there is assistance provided to ensure that the adult can appeal the decision to the Sheriff court in line with the requirements of articles 5 and 6 of the ECHR and article 13 of UNCRPD. To ensure that the right of appeal is effective the individual must be practically and actively assisted in the appeal process and allowed equity of access to the court.

- Once the medical treatment or assessment has been completed then it's important that the lead clinician sets an end date. The purpose of this is to lift the restriction measures and allow consideration of moving the patient to alternative more suitable accommodation. This would ensure mechanisms are put in place with the aim that when the patient is well enough that discharge is facilitated appropriately so they don't remain in hospital longer than necessary. The new guardianship process can be utilised if necessary at this stage including the use of new interim order discussed in this consultation.

Questions

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?

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?

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?

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

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?

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?

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

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

What the law says

Section 50 of the AWI Act currently sets out how to manage a situation where a guardian or welfare attorney or person appointed under an intervention order has

power in relation to medical treatment, and where disagreement arises about the desirability of treatment.

Section 50(2)(c) of the AWI Act provides that if there are individuals with 'welfare proxy' over an adult with incapacity, when a section 47 certificate is granted, the healthcare practitioner administering medical treatment must, where it is reasonable and practicable to do so, obtain the consent of the individual with welfare proxy.

There can be situations where the welfare proxy disagrees with medical treatment plans for an adult with incapacity and may withhold their consent to those plans. In these situations, where the healthcare practitioner has consulted the welfare proxy and they have a disagreement, the healthcare practitioner may seek resolution under section 50(4) of the AWI Act. This allows the healthcare practitioner to request the MWC to nominate another healthcare practitioner who the MWC considers has the relevant professional knowledge of the medical treatment in question to give a second opinion.

Section 50(5) provides that where the nominated healthcare practitioner certifies that having regard to all circumstances and consulting the welfare proxy, the proposed medical treatment should be given then treatment of the incapacitated adult can take place. Then the practitioner with the section 47(1) certificate may give or authorise treatment notwithstanding the disagreement with the welfare proxy.

Section 50(6) allows an appeal by the medical practitioner primarily responsible for the medical treatment of the adult or any person having an interest in the welfare of the adult against the nominated practitioner's decision that the treatment should or should not be given. This appeal is to the Court of Session.

The only situation where medical treatment authorised by section 47(2) may be given where an appeal has been made to the Court of Session and has not been determined, is where it is authorised by any other enactment or rule of law for the preservation of the life of the adult or the prevention of serious deterioration in an individual's medical condition. It should be noted that the scope of medical treatment authorised by section 47(2) is defined to mean any procedure or treatment designed to safeguard or promote physical or mental health. However, if a dispute over treatment is appealed to the Court of Session, where that treatment would amount to something less than a life-saving measure or the prevention of serious deterioration of someone's medical condition, it must not be given.

Section 50(7) therefore provides that giving medical treatment in the case of serious deterioration of health or the preservation of life is possible within the confines of the Act. If an interdict is handed down to stop the treatment, that right to treat would be removed immediately (section 50(8)).

The Adults with Incapacity Code of Practice for Medical Practitioners[45] states at paragraph 2.41". The division between cases where treatment is necessary for the preservation of life or to prevent serious deterioration, urgent cases, a necessity to treat and routine matters is not always clear-cut. What underlies the concepts of

[45] Adults with Incapacity: code of practice for Medical Practitioners

emergency and necessity is the issue of immediacy. The definition of emergency will vary slightly from specialty to specialty."

Paragraph 3.3 of the Code of Practice for Medical Practitioners says "Treatment in emergencies is specifically exempted from the scope of the Act. There is already common-law authority for a practitioner to treat a patient for the preservation of the life of the adult or the prevention of serious deterioration in his or her medical condition. There should be no question, therefore, of consultation putting a patient's life at risk."

What we are proposing

There can be circumstances where the giving of medication for the purpose of alleviating serious suffering on the part of the patient could also prevent serious deterioration in their medical condition. However, alleviation of serious suffering is not itself stated in the legislation or code of practice as a purpose for which treatment could be given while section 50 dispute resolution procedures are ongoing.

The Mental Health Act (Care and treatment) (Scotland) Act 2003[46] allows urgent medical treatment to be given to a patient detained in hospital without a second medical opinion (if that would otherwise be needed) for reasons that include any of:

- saving the patient's life
- preventing serious deterioration in the patient's condition
- alleviating serious suffering on the part of the patient

The Scottish Government believe that in a section 50 dispute resolution, the treating doctor should be able to give medical treatment that is necessary to alleviate serious suffering on the part of the patient (so long as there is no interdict in force). There is no mention of alleviation of serious suffering in the AWI Act Code of Practice for medical practitioners.

These changes would provide clarity for medical practitioners and relatives and medical staff when there is a dispute resolution situation, and they are providing treatment to the patient nearing the end of their life. This would require statutory changes to section 50(7) to reflect new policy intent rather than amending the code of practice for medical practitioners and make the AWI Act clearer on this matter.

Questions

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

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

[46] The Mental Health Act (Care and treatment) (Scotland) Act 2003

Use of force or detention

Section 47(7) of the AWI Act states that the authority given for treatment does not authorise the use of force or detention, unless it is immediately necessary, and only for so long as it is necessary in the circumstances.

The SMHLR considered this in chapter 13 of their final report. They gathered views from a number of respondents, the vast majority of whom said that there needed to be a tightening of the legislation and the practice. The MWC, the Royal College of Psychiatrists and the Scottish Human Rights Commission all expressed concern that the current provision was lacking in clarity and safeguards.

We agree with this and consider it necessary to provide for a scheme to set out where force or covert medication may be permitted. This requires further, detailed consideration so we are proposing that the AWI Act be amended to give Ministers the powers to by regulations create a scheme of authorisation for these actions. This will enable us to consult specifically on this issue in more detail prior to legislation. We will take forward work on this over the summer, and invite anyone who is interested in being involved in this to contact us at **awireform.queries@gov.scot**

We consider that the question of detention is dealt with by our proposals for an enhanced s47 certificate, hence the focus on force and covert medication in this section.

Exceptions to authority to treat

Section 48 of the AWI Act gives Scottish Ministers the power to specify by regulations, those medical treatments, or classes of medical treatments, which are not covered by a section 47 certificate.

Again the SMHLR considered this section, and noted concern that the treatments, and safeguards are different between the AWI Act and the 2003 Act. In principle the SMHLR were of the view that the same treatments should receive the same safeguards.

We agree with this, and will consult separately on how the current regulations may be amended to reflect the treatments and safeguards set out in the 2003 Act . This work will be taken forward over the summer months and again invite anyone interested in being involved in this to contact us at awireform.queries@gov.scot

PART 6

GUARDIANSHIPS

There has been dissatisfaction with the present guardianship system, dating back to the Public Guardian's paper on graded guardianship in 2011[47] . Concerns related to the pressures on the system leading to lengthy delays in getting a guardianship order. This resulted in delays in discharging people, often elderly, from hospital beds, with consequent deterioration in their condition.

We consulted on guardianship changes in 2018[48], publishing our summary and analysis shortly after[49]. The graded guardianship model reflected the aspiration to have a more flexible system, giving preference to the rights, will and preference of the adult in line with the UNCRPD.

However, feedback was that the proposed model did not achieve those aspirations. The consultation proposals were too wide ranging and risked creating more complex systems than before.

Since 2018, the pressures on the system have increased. At the same time there has been criticism that the AWI Act contains no emergency or urgent order provision. Taking this into account, in 2021 we undertook stakeholder engagement on a proposed AWI emergency or urgent order, to sit separately from the guardianship system.

The outcome of this work was that it was clear that such an order had to be integrated with the guardianship system. Many of the powers proposed related to further social care and therefore required a guardianship order for ongoing powers after the urgent order. Having two separate orders did not work. This consultation therefore proposes using an amended interim guardianship in cases of urgency.

Aside from the ideas we are consulting on here, there are numerous, technical changes to the AWI Act that we intend to take forward without consultation. They will result in more efficient use of the AWI Act and have been proposed by the Public Guardian and Law Society, with the majority also put forward by the SMHLR[50] .

We recognise that in the longer term the SMHLR recommends that there is a framework in place that ensures the will and preferences of the adult are first and foremost. This includes moving away from guardianships altogether, with a model of a decision making representative instead.

"The Decision Making Representative must act within the framework of Supported decision making and respecting the Autonomous decision making test (see Chapters 4 and 8 of the SMHLR respectively) and, where it is applicable, ensure the person's

---

47 Graded Guardianship

48 Download the consultation paper.

49 Summary and analysis of consultation responses

50 SMHLR

human rights are enabled, in line with the Human Rights Enablement (see Chapter 8)"[51].

Such a significant proposal for change takes time to consider and evaluate and may form part of a wider reform of mental health and incapacity law. In the short term we are taking a step towards this by ensuring that priority is given to the adult's will and preferences in the principles of the AWI Act, ahead of the other principles as set out in Part One of this consultation.

Guardianship law as it stands (sections 57-79A)

Presently, guardianship cases are decided by the Sheriff Court which is most local to where the adult lives. Guardians are appointed by the Sheriff.

An application to court is generally made by a solicitor who will ask the Sheriff to appoint the guardian(s), listing the welfare and financial powers which are requested. The application will give a brief background of the adult and the reasons for the guardian's appointment. It will also list any interested parties, in order that the Sheriff can instruct that they are sent a copy of the application.

The application has to contain certain reports as follows:

- A report from a registered medical practitioner, generally the adult's GP, from an examination carried out not more than 30 days before the lodging of the application. This should state that the adult is incapacitated in relation to the powers sought.
- A report from a doctor who has specialist experience in the diagnosis and treatment of mental disorder (where the incapacity is by reason of mental disorder), often a psychiatrist. Again, the examination has to be carried out not more than 30 days before the lodging of the application and it should state that the adult is incapacitated in relation to the powers sought.
- Where the application relates to the personal welfare of the adult, a report from a Mental Health Officer containing their opinion as to the appropriateness of the order sought. This will be based on an interview and assessment of the adult carried out no more than 30 days before the application is lodged. It will also contain their opinion on the suitability of the nominated individual to be guardian. In coming to their views, the Mental Health Officer will consider each of the principles of the AWI Act and seek out the views of the adult and interested parties.
- Where the application relates only to the property and financial affairs of the adult, then a report from a person who has sufficient knowledge to make such a report is required. This will follow the same format and have the same requirements as the Mental Health Officer report.

[51] Page 723 SMHLR

Once the application is received at court, it will then be sent back to the applicant with a court hearing date and an instruction from the Sheriff to send the application to interested parties, allowing them a reasonable time to respond before the hearing is due.

All interested parties can attend the hearing and have their say on the application. The Sheriff can continue the matter to another hearing for a number of reasons. These include ensuring all interested parties have received the application and had enough time to respond and to receive any further reports.

Once the Sheriff grants the guardianship, they inform the applicant and OPG of the powers granted. If there are financial matters the Sheriff may well have set an amount of caution that the guardian has to find before acting. This is an insurance bond to protect the adult against misuse of their funds. Once the guardian has found caution (if so required) then OPG will issue them with their certificate of appointment. If no caution is required, then OPG will issue the certificate of appointment on receipt of the order from the Sheriff.

Renewal of guardianship requires a further summary court application, including one medical report and appropriate Mental Health Officer and/or Public Guardian's report.

Our proposals

Medical reports

The need to obtain two reports from a GP and a psychiatrist, can result in delays in the application. Incapacity reports are not included in the GP contract and GPs are not obliged to carry them out. Where they do so they are entitled to charge for their services. GPs are not experts in incapacity assessments, so may not feel confident, or may refuse because of the volume of their existing work.

There are fewer psychiatrists, but they are experts at assessing incapacity where it results from mental disorder. It is generally part of their contract to complete incapacity reports. Even so, ideally the person completing the report should know the adult and psychiatrists may refuse if they are not familiar with the adult.

Given this difficulty we are considering reducing the number of medical reports required from two to one for guardianship applications, including interim applications. On balance we think that, in considering who should complete a single report where incapacity is by reason of mental disorder, the wider option of either a GP or a psychiatrist would be preferable. This pragmatically recognises the difficulty in getting these reports and also that one of the professionals may not be comfortable in providing a report for a particular patient. Where incapacity is by reason of inability to communicate because of physical disability we suggest that the single report should come from a GP. The vast majority of cases of incapacity under the AWI Act relate to mental disorder.

In reducing the requirement to one report, we are very conscious that this report needs to meet the needs of the case and provide sufficient information to enable the sheriff to make a decision. Clear guidance will set out what is required of the report, including the need to adhere to the principles of the AWI Act. If the sheriff is not happy with a report, there will be the option to request an additional report but we would hope, with appropriate guidance, a single report will provide adequate information in the majority of cases.

We are also proposing that clinical psychologists may be added as a third category of professional who can complete incapacity assessments for guardianship cases where incapacity is by reason of mental disorder. We think, given that the requirement is to assess incapacity, rather than diagnosing the mental disorder causing the incapacity, the skills and knowledge of a clinical psychologist would be of the appropriate level to assess incapacity by reason of mental disorder for the purposes of a guardianship order

Question:

49. Do you think the requirement for medical reports for guardianship order should change to a single medical report?

50. Do you agree with our suggestion that clinical psychologists should be added to the category of professional who can provide these reports (where the incapacity arises by reason of mental disorder)?

Mental Health Officer Reports

We know that delays in the obtaining of a guardianship result from an accumulation of delays in a number of different areas. One of the areas that has been brought up in the past is the Mental Health Officer report.

Recent Public Health Scotland statistics show that allocation of and completion of reports by Mental Health Officers is one of the biggest causes of delay in obtaining a guardianship order. There are numerous reasons behind this, one of which is the lack of Mental Health Officers.

The requirements of the Mental Health Officer report for a guardianship application are in regulations[52]. The Mental Health Officer has to consider each principle of the AWI Act which includes taking account of the views of the nearest relative and any person who may have an interest in the adult. We have been told that there can be delays where the Mental Health Officer tries to track down the opinions of every possible relative. We are considering whether the Mental Health Officer form for guardianship applications could be improved to make it more concise, whilst retaining the requisite information and would appreciate your views on this.

[52] See Schedule 2 of SSI 2002/96.

Questions:

51. Do you think the Mental Health Officer form for guardianships can be improved, to make it more concise whilst retaining the same information?

Person with sufficient knowledge reports for guardianship relating to property and financial affairs

This report has a wide qualification criteria for who can complete the report. Any person who has sufficient knowledge to complete the report[53] can do so, although they have to explain why.

The format of this report is the same as the Mental Health Officer report, so we are considering whether the same information can be provide in a more concise manner.

In addition, we have been told that the 'person with sufficient knowledge' report often is seen of little value. This is both because of the lack of detail but also because of the qualifications of the person completing the report. It may be a social worker, or it could be a friend or family member of the adult. We are interested in your views on whether this needs to change.

The first part of the report is a comment on the appropriateness of the order. The person with sufficient knowledge is required to state if the order will benefit the adult, if it is the least restrictive option, the wishes and feelings of the adult and the views of the nearest relative, primary carer, named person, guardian and relevant person(s). We would like to hear your views on whether the 'person with sufficient knowledge of the adult' should remain as the author of the report for a financial and property guardianship.

The second part of the report relates to the proposed guardian's suitability. OPG have in recent times introduced a guardian's declaration form[54] informally into proceedings.

This was introduced following the experience of OPG of the performance and preparedness of financial guardians once they had been appointed. Often OPG have found that appointed guardians had little or no knowledge of the reporting duties they were required to undertake as supervised by OPG.

Both the OPG form and the 'person with sufficient knowledge' form cover the proposed guardian's suitability. The OPG form requires a lot more detailed financial information than the second part of the 'person with sufficient knowledge' form. We think this information is more appropriately collected by OPG, who then provide a copy of the report to the court, with their own comments on the guardian's suitability

[53] Form AWI 8 (schedule 8): report to accompany application for guardianship relating to property and financial affairs
[54] Guardian Declaration

attached. This allows the sheriff to consider suitability and the OPG comments before appointment.

We therefore propose that the second part of the 'person with sufficient knowledge' report is no longer required. Instead we propose that in the same way an applicant has to give notice to the chief social work officer of their intention to make an application for guardianship with welfare powers [55]notice should be given to the Public Guardian for an application including financial powers. Following this the applicant will be required to complete and send the guardian declaration form to OPG. OPG will then submit this to court along with any comments on the suitability of both the guardian and the application.

Questions:

52. Do you think the 'person with sufficient knowledge' form can be improved, making it more concise whilst retaining the same information?

53. Should the person with sufficient knowledge continue to be the person who prepares the report for financial and property guardianship?

54. Do you agree with our proposal to replace the second part of the 'person with sufficient knowledge' report with a statutory requirement to complete the OPG guardian declaration form?

Sheriff discretion to consider MHO reports outwith 30 days limit

At present the sheriff has discretion to consider an application if the medical reports are out with the 30 day limit. This is only if the sheriff is satisfied there has been no change in circumstance since the examination and assessment was carried out[56].

We think the same discretion should be afforded to the sheriff in the case of Mental Health Officer reports. Presently we know of occasions when a report is just over the 30 day limit, with no change of circumstance. But the rigidity of the legislation requires a whole new report to be compiled, with the accompanying delay.

Question:

55. Should sheriffs be afforded the same discretion with Mental Health Officer report timings as they are with medical reports?

[55] S.57(4)

[56] S.57(3B)

Amendment of interim guardianship order for urgent cases

As mentioned above, there has long been a call for some type of 'urgent', 'emergency' or 'short term placement' order. We consulted in 2018 in chapter 10 of our consultation on the idea of a short term placement order[57]. Our analysis of the responses showed that out of 104 responses, 95 were in agreement with the proposal for a short term placement order and 9 were against. However the views of those who agreed were caveated with concerns around safeguarding and a need for more detail to be added.

We considered this proposal in more detail in 2021, with a stakeholder working group going into considerable detail. A variety of stand-alone (from guardianship) models were developed as the working group considered the issue. At the end the working group were of the view that a bespoke order was not compatible with the guardianship process.

Welfare guardianship orders invariably involve social care powers and are therefore ongoing, rather than time limited or one off powers. This makes them more suitable to guardianship orders. That meant that a separate, bespoke, short term placement type of order would always have to be followed up by a guardianship order, bringing potential for a gap in the orders, or a situation where the bespoke order might take longer than the guardianship order (on appeal for instance). Therefore it made more sense to focus attention on using the interim guardianship system.

At the moment a full guardianship order application is required in order for interim powers to be asked for. We propose that the AWI Act be amended so that an interim guardianship can be applied for separately and used swiftly where an urgent order is required, for instance where there is a need to move someone due to an imminent risk to their welfare.

An application for interim guardianship may be made to the sheriff court. A single medical report will be required. It will require an abbreviated MHO report, that will report only on the appropriateness of interim powers. This report will however still require to demonstrate the principles have been adhered to – in line with Part one proposals. Given the abbreviated nature of the report, we suggest that rather than a requirement to prepare this report within 21 days the requirement should be that it is prepared within seven days of notice being given to the local authority by the applicant. If a full guardianship order is considered necessary, the full report can be submitted to court in the usual timescale, with a hearing be scheduled on receipt of the full report.

We propose there should be a timescale of 5 calendar days, once the application is received by the court, for the sheriff to make a decision on the interim powers. We do not propose any change to length of time the interim powers can be sought for. At present interim powers can be sought for 3 months beginning with the date of

[57] Adults with Incapacity (Scotland) Act 2000 Proposals for Reform

appointment, with flexibility allowed to the sheriff to appoint for a longer period not exceeding 6 months. We recommend these timings remain.

Questions:

56. Do you agree that the best approach to cater for urgent situations is to amend the existing interim guardianship orders?

57. Do you agree that an abbreviated mental health officer report together with a single medical report should suffice for a guardianship order to be accepted by the court?

58. Do you agree that there should be a short statutory timescale for the court to consider urgent interim applications of this sort?

Variation of guardianship order to add financial or welfare powers

There may be situations where a guardian has been appointed with only financial powers and circumstances change so that welfare powers need to be added or vice versa.

At present the AWI Act requires that in both the above cases, a whole new application is required. That means a new summary application, two new medical reports and either a mental health officer report or a 'person with sufficient knowledge' report. This, as we know, will be very time consuming. Very often it will be well established that the adult lacks capacity by reason of the existing guardianship order, meaning that two new medical reports may not be necessary.

We think a more efficient way would be to require only the additional mental health officer report, or 'person with sufficient knowledge' report together with the OPG guardian declaration form, to be required. The sheriff can ask for more medical reports if required, but they should not be mandatory.

Question:

59. Do you agree that further medical reports are not required when varying a guardianship to add either welfare or financial powers?

Length of Guardianship orders

At present, an initial guardianship order can be made for 3 years, which can be increased to 5 years on renewal. However the Sheriff has discretion to appoint a guardian for 'such other period, including an indefinite period as, on cause shown, he may determine.'[58]

[58] AWI Act s58(4)

ECHR case law makes clear that there is a need for regular review of any restriction of a person's liberty and whilst guardianships do not necessarily restrict a person's liberty in all cases, they do by their very nature significantly impact on the adult who is subject to the guardianship.

Financial guardianships are subject to scrutiny by the OPG and welfare guardianships should be regularly reviewed by the local authority as set out in regulations[59]. Time limited guardianships should be subject to regular review by the Sheriff Court and either the OPG or local authorities, or both, depending on the type of guardianship.

Indefinite guardianships should be subject to regular review by OPG and/or local authorities, again depending on the type of guardianship. The MWC has stated that in certain specific cases, such as an elderly person with advanced dementia, indefinite orders are appropriate but such cases are limited.

In the majority of cases, periodical judicial scrutiny of orders should be the norm, as it removes the onus from the adult or another party to challenge the order if circumstances change. It should be noted however that the frequency of indefinite guardianship orders has reduced substantially in recent years, from 32% of orders in 2013-14 to 3.8% in 2022-23.[60]

However despite these safeguards, the review of guardianship orders has been criticised in a number of cases, in particular Aberdeenshire Council v SF[61] .
This case concerned a guardianship order in respect of an adult living in support accommodation in England but habitually resident in Scotland. The placement constituted a DOL which was ostensibly authorised by the guardianship order. The case was before Poole J, to seek recognition and enforcement of the guardianship order. The Court was required to conduct a limited review of the case.

Due to lack of evidence that the adult in question had been given an opportunity to give views to the court, and the wide powers given the guardian, namely that the order was proposed to be indefinite and was made for 7 years, the court did not recognise and enforce the particular guardianship order in this case. It stated to do so would be contrary to a mandatory provision of the law of England and Wales as it would breach article 5(4) of ECHR and therefore the Human Rights Act 1998. In his conclusion Poole J stated:

"Natural justice required that in a case where SF's liberty was being put into the hands of others for a period of seven years, she should have had an opportunity to be heard and/or an opportunity to be represented. SF's access to the court should not have been dependent on her taking the initiative. Effective access should have been secured for her. As it is, there were no measures taken to ensure that her Art 5(1) rights were upheld"

[59] SSI 2002/95 Adults with Incapacity (supervision of welfare guardians etc by local authorities)(Scotland) Regulations
[60] Adults with Incapacity Act monitoring report 2022-23
[61] Aberdeenshire Council v SF (No 2) [2024] EWCOP 10

It is of concern that in this case the principles of the AWI Act do not appear to have been followed. We would suggest that the changes proposed to the principles of the Act, set out in part one of this consultation should eliminate the possibility of the adult not being given an opportunity in the future to express their views to the court. However this does not address the question of the length of the guardianship order.

In this case an adult was placed under a guardianship order for 7 years, in circumstances that are quite different to those considered acceptable for indefinite guardianships by the MWC, such as elderly adults with advanced dementia. In light of this we wonder whether therefore we need to revisit the approach to length of guardianships generally.

In the next part of this consultation chapter we set out our approach to DOL and suggest time limits for guardianships which authorise deprivation of an adult's liberty.

But we would also be grateful for views on whether we need to change the current approach to length of guardianship orders more generally, and in particular if there is a need to remove discretion from the sheriff to grant an indefinite guardianship order.

In doing so, we need to consider the application of the AWI Act principles, namely whether in every case there will be a benefit to the adult in requiring them to go through the renewal procedure. And if we do continue with the sheriff's discretion to grant an indefinite guardianship, what safeguards would need to be put in place to ensure regular reviews take place and account can be taken of changes in circumstances.

Question

60. Does the current approach to length of guardianship orders provide sufficient safeguards for the adult?

61. Do changes require to be made to ensure an appropriate level of scrutiny for each guardianship order?

62. Is there a need to remove discretion from the sheriff to grant indefinite guardianships?

63. If you consider changes are necessary, what do you suggest they would be?

Adding additional exclusions to AWI Act

The AWI Act presently states that there are some things that a guardian or an attorney may not do. They are very limited lists of powers and are identical for guardians and attorneys. There is no equivalent list for interveners.

At the moment the following powers are excluded from guardians and attorneys in the AWI Act:[62]

- Place the adult in a hospital for the treatment of mental disorder against their will;
- Consent on behalf of the adult to any form of treatment in relation to which the authority conferred by section 47(2) does not apply by virtue of regulations made under section 48(2);
- Make, on behalf of the adult, a request under section 4(1) of the Anatomy Act 1984 (c. 14);
- Give, on behalf of the adult, an authorisation under, or by virtue of, section 6(1), 16F(1)(a),17, 29(1) or 42(1) of the Human Tissue) Scotland) Act 2006 (asp 4);
- Withdraw an authorisation, on behalf of the adult, by virtue of section 6A(1) of that Act;
- Make, on behalf of the adult, an opt-out declaration by virtue of section 6B(1) of that Act;
- Withdraw an opt-out declaration, on behalf of the adult, by virtue of section 6C(1) of that Act; or
- Make, on behalf of the adult, a nomination under section 30(1) of that Act

Over the past 20 years in the operation of the AWI Act, it has become clear that it would be helpful to add to this list of exclusions to clarify the roles and responsibilities of guardians and attorneys.

Question

64. We propose that the following powers should be added to the list of actions that guardians, attorneys and interveners should be expressly excluded from. Do you agree?

    - consenting to marriage or a civil partnership,
    - consenting to have sexual relations,
    - consenting to a decree of divorce
    - consenting to a dissolution order being made in relation to a civil partnership
    - consenting to a child being placed for adoption by an adoption agency,
    - consenting to the making of an adoption order,
    - voting at an election for any public office, or at a referendum
    - making a will
    - if the adult is a trustee, executor or company director, carrying discretionary functions on behalf of them,
    - giving evidence in the form of a sworn affidavit

65. Are there any other powers you think should be added to a list of exclusion?

[62] S16(6) and s.64(2)

PART 7

APPROACH TO DEPRIVATION OF LIBERTY (DOL)

The Bournewood [63]and Cheshire West[64] court cases which are decisions that are binding in England and Wales have nonetheless highlighted concerns that there is a human rights gap in Scots law around the DOL for persons who lack capacity to consent to this voluntarily.

Article 5 of the ECHR permits DOL for 'persons of unsound mind', subject to safeguards intended to prevent unjustified detentions. It requires a lawful process to authorise a DOL, even in those cases where there is no objection from the adult or their family. And this detention must be able to be challenged in a practical and effective way.

The Bournewood case made it clear that if a person is subject to continuous control and supervision and is not free to leave, then article 5 is engaged. And it said that a person who lacks capacity but does not seem to object to a deprivation cannot consent to that DOL.

The Cheshire West case reinforced this position. We consider it important to review situations in health and social care where DOLs may occur and what safeguards might be required.

The 2003 Act provides Article 5 ECHR compliant safeguards against unjustified or unlawful DOL with the legal framework it established for compulsory measures of care and treatment. But Bournewood and Cheshire West have highlighted the need for us to consider DOL in other Scottish health and social care settings.

This was considered in detail by the Commission in their 2014 report[65]. This concluded that there is a lack of legal process for adults without capacity in both hospitals and care home facilities in Scotland.

The position of adults in hospital is considered in part 5 of this consultation. This part of the consultation considers the position of adults in social care settings.

What do we mean by DOL?

There is no single definition of the concept of DOL in ECHR case law. But the case law can be used to identify a number of factors that are relevant in trying to set out a definition.

DOL includes an objective and a subjective element. A person with capacity can give valid consent to measures restricting their liberty and article 5 is not engaged.

---

[63] HLvUK (45508/99)[2004]ECHR471
[64] Cheshire West and Chester Councilv P[2014] UKSC 19
[65] Report on Adults with Incapacity 2014 SLC 240

Objectively however DOL takes into account the situation of the individual concerned and considers a whole range of criteria such as the type, duration, effects and manner of implementation of the measure in question.

The distinction between a DOL, and restrictions upon a person's liberty is one of degree or intensity rather than nature or substance. It is about how measures are applied rather than what they are or where they are applied. But the key factor is whether the person is under the continuous supervision and control of those responsible for their care and whether the person is free to leave.

We had considered setting out a definition of DOL in legislation, however, the SLC report at para 7.6. said

' we do not make a recommendation that the 2000 Act be amended to define the terms 'detention and DOL ' Several consultees suggested in their responses that a workable definition of those terms is likely to be extremely difficult to achieve, In addition, as the Faculty of Advocates pointed out the application of Article 5 ECHR necessarily involves the balancing of a number of factors relevant to any given situation. It is questionable to what extent the inclusion of specific definitions would be consistent with that. '

We agree with this. We consider that a better approach is to set out in the code of practice and guidance, what factors need to be considered in assessing whether an adult will be subject to a DOL, or restrictions on their liberty, or not. This will ensure the factors relevant to each case are properly considered. Guidance and changes to the codes of practice will be fully consulted on in due course. We propose however that the term 'deprivation of liberty 'is used in legislation as it is well understood.

We are here concentrating on DOL, but we are aware that there are views that restrictions on liberty short of depriving someone of freedom to come and go as they please from their place of residence, should also be subject to additional safeguards.

We have said in part 5 of this consultation that we will be developing a scheme in regulations, which will be consulted on in due course to address the perceived lack of safeguards around the use of force and restrictions in cases of treatment under section 47 of the AWI Act but would welcome views on whether we need to go further than this.

What steps are required?

The **SMHLR** considered the question of DOL in chapter 8 of its final report.

At 8.3.1 page 263 we note the following excerpts:

'There has therefore been an increasingly urgent need to address this incompatibility and ensure there is a process to authorise lawful DOL, and to challenge the lawfulness of a DOL. At the same time any process must be a proportionate one which does not discriminate against disabled people relative to others. For example, it is disproportionate to suggest that in the absence of any concerns, an adult living

in a domestic setting with family or foster care style relationships should be treated as being deprived of their liberty and the family subject to monitoring by the State. […]

…it is discrimination to deprive someone of their liberty where they are unable to consent to this if the only reasons for doing so is the convenience of those providing care and support, or because of misconceptions about the level of risk they present to themselves or to others, or to protect them from abuse by others.

This poses something of a dilemma in human rights terms. On the one hand article 5(1)(e) ECHR allows for a person to be deprived of their liberty subject to safeguards, where there is a reliable diagnosis of unsound mind (Winterwerp[66]). On the other hand […] the committee on the Rights of Persons with Disabilities has stated this is discrimination. However, we consider that this apparent mismatch of approaches between the two treaties can be significantly reduced, […] by virtue of the Human Rights Enablement, Supported Decision Making and Autonomous Decision Making framework as described in chapter 4.

An objective of such a framework would be to ensure that whenever someone is deprived of their liberty, this is either a reflection of their will and preferences, (using SDM) or where it is not it is only possible if […] a risk exists to their or other's rights that proportionately and non- discriminatorily warrants a DOL and must be in fulfilment of the person's overall human rights. […]

We recognised that in order to provide care and support so as to protect a person's overall rights, including their safety and wellbeing, a DOL may occasionally be necessary.

Clearly any person who can, is able to make an autonomous decision to express their consent to their living arrangements, even where these might amount to a DOL, and this must be respected. We also felt that where a person cannot make an autonomous decision but can, with support, express a will and preference to remain in their current living arrangements, even if those arrangements would otherwise constitute a DOL there was no need for further judicial oversight.''

The Scottish Government agrees with this approach. Although at this stage in law reform we are not tackling the proposals for human rights enablement and autonomous decision making, as proposed by the SMHLR, work is underway to develop a supported decision making framework, which will underpin proposed changes to the AWI Act and practice.

So, we consider that a pragmatic approach as proposed by the SMHLR is appropriate for many potential DOL placements where a person can be supported to express their will and preferences. If a person with support can clearly express a will and preference to remain in their living situation, even if that situation is a DOL, no further judicial oversight is required. However, as we state later in this chapter, we

[66] Winterwerp v Netherlands (6301/73[1979]ECHR 4

are proposing a stand-alone right of appeal similar to that proposed by the SLC report, and this would be available to anyone in these circumstances.

People who cannot consent to a DOL

Again, the SMHLR considered this in chapter 8 of their final report. They proposed that both a power of attorney and authorisation of a decision making representative could facilitate a DOL.

A decision making representative is the alternative to guardianship that the SMHLR proposed. At this stage in law reform, we are not considering this change, however, we consider that the proposal for a decision making representative to facilitate a DOL can be read across to guardianships.

Powers of Attorney

The SMHLR proposed that a power of attorney (POA) with prescribed wording, may grant advance consent for the attorney to deprive the granter of their liberty, where the deprivation is proportionate and will demonstrably lead to more respect, protection and fulfilment of the person's rights overall.

We agree with this, but the proposal needs further detail which we provide here.

In Part 1 of this consultation, we have set out the changes that will be taken forward in any future law amending the AWI Act. One of these changes is to require that in creating a power of attorney, the granter must set out how a determination of their incapacity should be decided.

If the power of attorney is to include advance consent to deprive the granter of their liberty, we propose that this incapacity will require to be determined by independent medical assessment.

As to the terms of the power of attorney, we do not intend that any change will affect the current provisions of section 16(6) of the AWI Act. The prohibition on placing a granter in hospital for the treatment of mental disorder against their will, and accompanying restrictions will continue to apply.

Section 16(3) of the AWI Act sets outs the terms that need to be met to ensure the validity of a welfare power of attorney. We suggest that this be amended to reflect the wording required for a power of attorney to authorise a DOL of the granter and that if the required wording is not followed, the POA cannot validly authorise a DOL.

We anticipate that any Bill will contain a power for Ministers to specify the wording by regulations and this will be consulted upon at a later date, but we consider that the following factors will need to be reflected in the wording

- The granter has considered the circumstances in which it might be necessary to restrict their liberty or deprive them of their liberty, in order to safeguard their health or welfare, or that of others.
- The terms of article 5 of the ECHR have been explained to the granter

- Authority is given to the attorney/s alone
- The attorney must be satisfied the action is necessary to safeguard the health or welfare of the granter
- The attorney must act in accordance with the principles of the AWI Act
- The attorney will be subject to any directions of the court following any application under section 3 (3) of the AWI Act.

This last point is particularly important. We propose that where an adult,having previously granted advance consent for their attorney to deprive them of their liberty, later objects to the consent being acted on, and their being moved to a setting where their liberty is restricted or deprived, the attorney, or any other person with an interest in the adult's welfare must seek a determination from the Sheriff under section 3(3) as to the appropriate way to proceed.

Appeal and Review

As stated above any process to deprive an adult of their liberty must be challengeable in a practical and accessible way. So, we suggest that an appeal may be made to the sheriff court, by any person demonstrating an interest in the welfare of the adult.

The grounds for appeal should be that the placement is not necessary to safeguard the health or welfare of the granter. In keeping with the proposed amended principles of the AWI Act as set out in part 1 of this consultation, there would be a requirement on the person raising the appeal, to demonstrate what steps had been taken to ascertain the views of the adult. The sheriff would also have the option of appointing a safeguarder (the position of safeguarders and curators is set out later in this part.)

It is important that the appeal process be accessible. We would welcome views on what added steps can be taken to improve the accessibility of the appeal process.

Review of the placement

In keeping with the principles of the AWI Act it is important to ensure that an adult is subject to the least restrictive option in relation to the freedom of the adult consistent with the purpose of the intervention. So, an adult deprived of their liberty should only be subject to these restrictions for the minimum time necessary. To that end regular reviews of the placement/ restrictions will be needed. And such regular reviews are also needed to meet ECHR requirements.

We are seeking views on how regular reviews can be carried out. At present the local authority is obliged to review guardianship orders every 12 months[67]. There is no such requirement for powers of attorney. Whilst there is a balance to be struck between ensuring the safety and wellbeing of an adult, and recognising that, in the case of a power of attorney, actions are carried out in accordance with the adult's specific instructions, when it comes to an individual being deprived of their liberty it is essential to ensure this situation is not abused in any way.

We therefore seek views on how DOLs authorised by a power of attorney can be appropriately reviewed, in a way that is accessible to the adult.

Guardianship orders

At present guardianship seems to be accepted as a lawful procedure under ECHR to deprive a person of their liberty[68]. But concern has been expressed that the voice of the adult is not at the centre of the process.

Section 64 of the AWI Act sets out the functions and duties of a guardian. We think it is important to add to these functions and duties the position around DOL

Our policy proposal is that specific provision is made whereby, on cause shown, the sheriff can authorise a guardian to place an adult in a setting which may form a DOL.

The cause shown would need to meet ECHR requirements, so

- An independent medical assessment of mental disorder would be needed – the current requirements for medical reports for guardianship applications, as amended by our proposed changes would address this we think
- The placement would need to be time limited, and subject to regular reviews. This should be a combination of regular internal reviews and a time limit placed on the authorisation by the sheriff.
- We propose that the initial order should be for a maximum of 12 months, which may on renewal be extended to a maximum of 2 years, in keeping with the requirement for regular reviews of detention [69]
- The placement would need to be a proportionate response to the situation the adult is facing. i.e. that it was necessary to safeguard the welfare or health of the adult.
- The principles of the AWI Act would still need to be followed, so the will and preferences of the adult would need to be ascertained

A right of appeal will be created, in similar terms to that for placements under a power of attorney, by any person demonstrating an interest in the welfare of the adult. The grounds for appeal should be that the placement is not necessary to safeguard the health or welfare of the granter. In keeping with the proposed

[67] The Adults with Incapacity (Supervision of Welfare Guardians etc. by Local Authorities) (Scotland) Regulations 2002 (as amended)
[68] KvArgyll and Bute Council [2021]SAC (civ) 21
[69] Stanev. V Bulgaria (App 36760/06)(2012) 55 EHRR 22

amended principles of the AWI Act as set out in part 1 of this consultation, there would be a requirement on the person raising the appeal, to demonstrate what steps had been taken to ascertain the views of the adult. The sheriff would also have the option of appointing a safeguarder (the position of safeguarders and curators is set out later in this part.)

And again, we would welcome views on what added steps can be taken to improve the accessibility of the appeal process.

Review of the placement

Currently welfare guardianship orders are subject to a requirement for an annual review by the relevant local authority. This generally consists of a visit from a social worker or Mental Health Officer. We consider however that a placement where an adult is being deprived of their liberty requires a more regular review and are recommending that a review every six months by the local authority should be undertaken for such placements. The adult, and /or any person demonstrating an interest in the welfare of the adult, may also request a review of the placement at any time.

We would like your views on whether these proposals are sufficient or if more needs to be done to ensure such placements are appropriately reviewed and what format the review should take.

Stand-alone right of Appeal

In its 2014 report the SLC recommended a stand-alone right of appeal against any detention which could be assessed as being unlawful. We agree with this proposal.

As said earlier in this part, we consider that if a person is able with support to express their will and preferences, and agree to remain in their current living environment, even if such an environment forms a DOL, then no further judicial oversight is required. However, if this situation should change then the adult needs to have a means of addressing this.

We would hope that regular internal reviews, and dialogue with the adult, supporting them to express their will and preferences would ensure steps could be taken quickly should the adult no longer be content with their placement. However that cannot be guaranteed, and we consider a stand-alone right of appeal against a DOL is needed for such scenarios.

As with the appeal proposed against placements under a power of attorney and a guardianship order, an appeal should be able to be raised by any person demonstrating an interest in the adult. And the appellant will have to demonstrate how the will and preference of adult has been obtained.

Role of the Mental Welfare Commission

Section 9 of the AWI Act sets out the specific functions of the Mental Welfare Commission (the MWC) in relation to any adult to whom the AWI Act applies by reason of mental disorder. That is, the MWC has no role in relation to adults whose incapacity results solely from inability to communicate.

Currently the MWC must consult the Public Guardian and any local authority on cases or matters relating to the exercise of the AWI Act where there is, or appears to be a common interest; if the MWC is not satisfied with any investigation made by a local authority, into a complaint made under section 10 of the AWI Act, or where the local authority have failed to investigate the complaint the MWC may investigate complaints relating to the personal welfare of the adult made in relation to welfare attorneys, guardians or persons authorised under intervention orders.

The SMHLR recommended that the MWC may intervene if they have concerns, in cases where an adult has with support, expressed a will and preference to remain in their current living arrangements, even if those arrangements constitute a DOL

We agree with this but we think the role of the MWC should be extended to permit them to investigate any placement where an adult is deprived of their liberty under the AWI Act, if concerns are raised with the MWC by any person having an interest in the adult's welfare, or by the MWC themselves in the course of a visit to the adult from a Commission visitor, under section 13 of the Mental Health (Care and Treatment)(Scotland) Act 2003.

Questions

66. Do you agree with the overall approach we are proposing to address DOL?

67. Is there a need to consider additional safeguards for restrictions of liberty that fall short of DOL?

Powers of attorney

68. Do you agree with the proposal to have prescribed wording to enable a power of attorney to grant advance consent to a DOL ?

69. What are your views on the issues we consider need to be included in the advance consent?

70. What else could be done to improve the accessibility of appeals?

71. What support should be given to the adult to raise an appeal?

72. What other views do you have on rights of appeal?

73. How can DOLs authorised by a power of attorney be appropriately reviewed?

Guardianships

74. Do you agree with the proposal to set out the position on DOL and guardianships in the AWI Act?

75. In particular what are your views on the proposed timescales?

76. What are your views on the proposed right of appeal?

77. What else could be done to improve the accessibility of appeals?

78. Do you agree with the proposal to have 6 monthly reviews of the placement carried out by local authorities?

79. Is there anything else that we should consider by way of review?

Stand-alone right of appeal

80. Do you agree with our proposal for a stand-alone right of appeal against a deprivation of liberty?

Role of the MWC

81. Do you agree with our proposal to give the MWC a right to investigate DOL placements when concern is raised with them?

Appointment of Safeguarders/Curators ad litem

Part one of our consultation paper proposes that there should be an overarching new principle for the AWI Act, that before any steps are taken to intervene in an adult's life, all practicable steps should be taken to ascertain their will and preferences, and thereafter any action should be taken in accordance with these.

It follows that in court proceedings under the AWI Act, such as applications for guardianship, it is really important that every effort is made to find out the views of the adult before decisions are made.

In the long term the Scottish Government is considering a substantial revision of mental health and capacity law, but for present purposes, we are looking to improve

the way the current systems work, so there is a need to ensure that the methods currently used to ensure the voice of the adult is fully heard, are working.

At present, safeguarders and curators ad litem play crucial roles in legal proceedings involving vulnerable individuals, and they are often appointed by the sheriff in AWI cases to ensure the adult's views are heard.

Safeguarders are appointed by the court to represent and safeguard adults with incapacity in legal proceedings. Their primary responsibility is to ensure that the views, wishes and welfare of the adults they represent are fully considered and represented within the legal process.

Curators ad litem are appointed by the court to provide independent representation for individuals who are unable to represent themselves effectively in legal proceedings. They serve as a vital link between the court, their clients, and relevant stakeholders such as Mental Health Officers, facilitating communication and ensuring that decisions are made for the benefit of those they represent.

Safeguarders and/ or curators ad litem generally have a background in law, social work, or a related field, with experience working with vulnerable individuals.

Some cases involving adults with incapacity can be highly complex, requiring a nuanced understanding of legal, medical and social issues.

There is a gap in terms of public awareness and understanding of the roles of safeguarders and curators ad litem. This can lead to misconceptions and challenges in implementing effective measures for both roles.

Concerns around the understanding of the role of both safeguarders and curators are long standing. Lord Gill in the Scottish Civil Courts Review in 2009 recommended changes such as uniform training programmes, minimum standards and national standards and rates of remuneration. The appointment of curators ad litem in the Mental Health Tribunal for Scotland has been revised but no new process has been introduced in the Sheriff Courts for AWI cases. Similarly the role and responsibilities of safeguarders in the children's hearing system has been revised, but no such action has been taken in respect of safeguarders for AWI cases.

Chapter 5 of the final report of the SMHLR looked at the roles of both safeguarders and curators ad litem. The main issues around curators ad litem mentioned in the review include:

- variances in understanding the role, with some seeing it as representing the individual's best interests and others as stepping into the individual's shoes
- lack of formalised training for curators ad litem, particularly concerning when working with individuals with neurodiverse conditions or sensory impairments
- absence of statutory obligation to produce reports, leading to inconsistencies in quality and detail

- limited opportunities to develop trusting relationships between curators ad litem and individuals due to appointments being made on a case-by-case basis
- disparities in rights of appeal compared to other roles, such as in cases of AWI where curators ad litem have limited appeal rights
- suggestions for exploring the need to reconsider the right of appeal for curators ad litem in Mental Health Tribunal for Scotland (MHTS) cases.

The main issues with safeguarders mentioned in the review include:

- overlap and lack of distinction between the roles of safeguarders and curators ad litem, leading to confusion
- suggestions for consolidating the roles to reduce confusion and streamline the process
- concerns about common procedures for appointments of both roles across Scotland, leading to inconsistency
- uncertainty regarding payment for safeguarders, with councils covering the cost but no clear basis for charging
- calls for uniform training programs and national standards to ensure consistency and best practice
- discussion about the potential role of an Official Solicitor in Scotland, similar to the one in England, to represent individuals lacking mental capacity and unable to manage their own affairs.

Chapter 5 of the SMHLR also recommends that the Scottish Government should increase governance over the role of a curator ad litem. This should include:

- a statutory duty on the curator ad litem to report the actions they have taken to ascertain the will and preference of the individuals
- mandatory training for curators
- establishing a process for ensuring that there is no conflict of interest where a curator ad litem also acts as a solicitor.

For safeguarders, Chapter 5 of the SMHLR recommends the Scottish Government should:

- review guidance to ensure that there is a consistent approach to appointing safeguarders across all sheriffdoms
- review guidance to ensure that the role of the safeguarder is unambiguous;
- create a uniform training programme with a requirement that the training is completed before being accepted as a safeguarder

- create a system of national standards for the work being done which would enable best practice to be shared across the country
- revise the payments system for safeguarders to place it on a more equitable footing.

In addition to considering the recommendations of the SMHLR, officials from the Scottish Government met with the former Public Guardian for Scotland to discuss the roles of safeguarders and curators ad litem. From this it was clear that while both roles serve essential functions, there are areas for improvement, particularly in ensuring consistency, transparency and accountability in their appointments and decision-making processes. These insights not only closely correspond with the recommendations outlined in the SMHLR but also helped inform our proposals for change, aimed at effectively addressing the identified areas of improvement for both roles.

We agree with the recommendations set out in in the SMHLR for both safeguarders and curators ad litem. There is a need for consistency of approach and transparency of appointment to both roles, and the tasks they are expected to complete.

There is a distinction to be drawn between the appointment of safeguarders and curators. Safeguarders for adults are only used in AWI cases in the sheriff court where as curators ad litem can be used in other proceedings.

For safeguarders therefore we are proposing a power for Ministers to make regulations that will establish a scheme for the appointment and training of safeguarders. This scheme will also set out a payment scheme for safeguarders. The aim of this will be to ensure consistent quality of reporting and a greater understanding of the role and responsibilities of the safeguarder.

For curators, we are proposing mandatory training for AWI cases and a duty to report the actions they have taken to ascertain the will and preferences of the adult they are working with. We are proposing a statutory duty for curators ad litem to report the actions they have taken in order to ascertain the will and preference of the individuals they represent. This will be taken forward in regulations which will be consulted on.

Again we hope that this will improve understanding of the role of the curator, and ensure the adult’s voice is heard.

However it may be that more support is needed for adults with incapacity within court proceedings. We would be grateful for views as to what additional support may be required to ensure court proceedings under AWI are more accessible for adults with incapacity,

Questions:

82. Do you agree with the proposals to regulate the appointment, training and remuneration of safeguarders in AWI cases?

83. Do you agree with the proposals for training and reporting duties for curators?

84. What suggestions do you have for additional support for adults with incapacity in AWI cases to improve accessibility?

Making financial abuse of an adult lacking capacity a criminal offence

Presently the AWI Act states that it is a criminal offence for anyone with powers under the AWI Act relating to the personal welfare of an adult to ill-treat or wilfully neglect that adult[70].

A person guilty of this offence is liable on summary conviction to imprisonment for a term not exceeding 12 months or to a fine not exceeding the statutory maximum or both. On conviction on indictment a person guilty of this offence is liable to imprisonment for a term not exceeding 2 years or to a fine, or both.

We are suggesting that there is an equivalent criminal offence for financial abuse of an adult lacking capacity, with similar liability as welfare. We know that welfare and financial abuse often come hand in hand. We hear that because of a lack of a specific criminal offence under the AWI Act, there can be uncertainty over whether a criminal offence has occurred, or whether it is a civil matter.

We think financial abuse of an adult lacking capacity is a criminal matter and whilst it can be prosecuted under other criminal charges like embezzlement, fraud or theft, there is merit to having a specific criminal offence of this kind. Adults with incapacity are one of the most vulnerable sectors in our society and already have a specific welfare offence of ill-treatment and wilful neglect. As such we think they deserve the profile of having a specific offence of financial abuse.

Question:

85. Do you think there should be a specific criminal offence relating to financial abuse of an adult lacking capacity?

86. If so, should the liability be the same as for the welfare offence?

Safeguards whilst awaiting discharge from hospital

The proposals contained within this consultation aim to streamline and improve the AWI process, enhance the rights of incapable adults and address the challenges around deprivation of liberty for incapable adults.

[70] AWI Act S.83

We know that nearly 20% of all delayed discharges are people in hospital settings, recorded as being adults with incapacity. These can be in-patients for planned care such as a hip replacement, or as an emergency through Accident and Emergency.

Clinicians will ensure that they receive the most appropriate care to support them to become clinically fit to be discharged. If someone is deemed not to have the capacity to make decisions on their own, as to the care and support needed at this stage and in particular where they might live, provisions under the AWI Act can be used.

Some patients will have made provision for this kind of situation by granting power of attorney to a friend or relative to make decisions on their behalf. However, if no such provision is in place, or the PoA does not give authority for the set of circumstances the adult is faced with, and the adult even with support is unable to make decisions for themselves, a welfare guardianship may be required. This process can take time, as it rightly ensures that the rights of the individual are fully protected.

This accounts for nearly 400 people each week who, despite no longer needing hospital care, are currently staying in that hospital rather than in a setting that would be more appropriate. In many circumstances this is not the least restrictive option to meet their health and care needs. Within the hospital setting, people are often disconnected from their families, friends and social connections which impacts on their rights to respect for private and family life.

Of particular concern is the duration of discharge delay for those that are classified as AWI-related delays. Compared to ‘standard delays,’ whose average length of delay is 16 days, we know that this increases to 66 days for AWI.

Part 2 of this consultation set out proposals for change to powers of attorney, Part 6 of the consultation sets out proposals for change to guardianship orders, and later in Part 7 of the consultation, we have set out the suite of options proposed to address the challenges around deprivation of liberty and incapable adults.

We are very interested to hear your views on whether there are additional steps that could be implemented to ensure those individuals, who are a delayed discharge from hospital and who are currently going through the guardianship process, could be moved out of an acute setting and into a more appropriate care setting. An example would be a care home, that better meets their needs, while ensuring their rights are safeguarded.

We are also interested in your views on using different care settings, out with the NHS, for those who no longer need acute hospital care but for whom the guardianship process has not yet concluded.

Questions

87. Do you have experience of adults lacking in capacity being supported in hospital, despite being deemed to be no longer in need of hospital care and treatment? What issues have arisen with this?

88. Do you foresee any difficulties or challenges with using care settings for those who have been determined to no longer need acute hospital care and treatment?

89. Are there any safeguards we should consider to ensure that the interests and rights of the patients are protected?

90. What issues should we consider when contemplating moving patients from an NHS acute to a community-based care settings, such as a care home?

PART 8

PROPOSALS TO AMEND THE AWI ACT IN RESPECT OF THE GOVERNANCE OF INCAPACITATED ADULTS PARTICIPATING IN RESEARCH

We are proposing a number of changes to Section 51 of the AWI Act and its associated Regulations (The Adults with Incapacity (Ethics Committee) (Scotland) Regulations 2002). This legislation governs the circumstances in which incapacitated adults can be involved in research as participants. These proposals would reform the processes for participation in research and the ethical review of research proposals involving adults with incapacity in Scotland. It is the intention that any amendments to legislation support high quality research that underpins a modernised, resilient and sustainable health system, while ensuring ethics review processes are efficient and robust, with the rights, safety, dignity and wellbeing of research participants prioritised throughout.

Background

As previously mentioned, there was a substantive consultation on AWI reform in 2018. Included in this consultation were proposals to reform the processes under which incapacitated adults can participate in research studies in Scotland. Responses to these proposals were received from a range of relevant stakeholders, including clinicians, organisations and members of the public. While broadly supportive, it was clear that the majority of respondents sought greater clarity and detail on these important reforms. A summary and analysis of the 2018 consultation responses was published by the Scottish Government[71].

In response to this, the Scottish Government agreed to develop a focused set of more detailed proposals to amend Section 51 of the AWI Act that governs research, and how such amendments would impact adults with incapacity participating in this research. To assist in the development of these more detailed proposals, the Scottish Government's Chief Scientist Office (CSO) set up a Working Group which was also tasked with clearly describing the approvals required before different types of studies can commence recruitment, and how and why the law, and therefore the approval system, is different for adults with incapacity in Scotland.

The group have developed a number of examples of real life scenarios depicting the effect of the current law in Scotland compared to the research environment across the UK; and have contributed towards the Scottish Government formulating a number of proposals that outline how the AWI Act could be amended to change both the manner in which incapacitated adults can participate in research, and how the ethical review of research studies involving these individuals is carried out. This part of the consultation sets out these proposals for reforming Section 51 of the AWI Act, and seeks views and comments from a wide range of stakeholders

[71] Adults with Incapacity Reform

Summarising the proposals

Upon its enactment in 2000, the AWI Act was a pioneering piece of legislation that enshrined the rights of incapacitated adults. These proposals outline amendments that aim to modernise and update how the AWI Act governs the manner in which incapacitated adults can participate in research. Whilst each proposal is expanded on and contextualised in later sections, in some instances with accompanying case studies, the proposals can be summarised as follows:

- Being allowed to establish more than one ethics committee that is capable of reviewing research proposals involving incapacitated adults in Scotland.
- Permitting adults with incapacity to be included in research studies without consent for those types of studies where consent is already not required from adults with capacity.
- Affording adults with incapacity the opportunity to participate in research studies that investigate conditions other than those responsible for their incapacity.
- Permitting waivers of consent to be applied in emergency situations to involve adults with incapacity in research in cases where it is not reasonably practical or feasible to seek consent from the individual's guardian, welfare attorney or nearest relative.
- Expanding the list of individuals permitted to provide consent for adults with incapacity to take part in research.

Definitions

Defining research

Section 51 of the AWI Act specifically provides governance for how adults incapable of giving consent can participate in medical, surgical, dental, nursing or psychological research, subject to certain safeguards and exceptions.

In practice, this typically corresponds to the AWI Act governing activities that would fall within what is considered 'health and social care research'.

The Health Research Authority (HRA) – a UK organisation that aims to safeguard the rights and interests of patients and members of the public involved in health and social care research – describes the role of health and social care research as the following[72]:

> *"*Health and social care research aims to find out new knowledge that could lead to changes to health treatments, policies or care. Without health and social care research, clinicians (doctors, nurses, dentists, social workers, and other health professionals) would continue to carry out their work the same way without knowing if a new treatment or approach would be more effective for the person they are supporting or treating*."*

[72] NHS Health Research Authority. How we regulate health and social care research. 2018.

The UK Policy Framework for Health and Social Care Research[73] is a set of guidelines that outlines principles of good practice and conduct in the area of health and social care research. The following definition of 'research' is adapted from the one provided in this Framework:

> "Research is defined as the attempt to derive generalisable or transferable new knowledge to answer or refine relevant questions with scientifically sound methods. This excludes audits of practice and service evaluations. It includes activities that are carried out in preparation for or as a consequence of the interventional part of the research, such as screening potential participants for eligibility, obtaining participants' consent and publishing results. It also includes non-interventional health and social care research (i.e. projects that do not involve any change in standard treatment, care or other services), projects that aim to generate hypotheses, methodological research and descriptive research."

For clarity, throughout this consultation, any mention of 'research' is broadly in reference to activities or projects that would fall under the banner of health and social care research.

Research can take many forms: testing out new potentially life-saving drugs, studying blood samples or data provided by patients, or asking participants to fill out a survey or questionnaire. Research studies may involve a limited number of people, or several thousand. It may be conducted within a comparatively small geographical area, or it may be worldwide. The length of time a trial runs will also vary, and participants will be told the duration of the study before it begins.

However, regardless of the type of research performed in the health and social care sector across the UK, it is rigorously regulated, and many safeguards are in place to protect the rights, wellbeing, safety and dignity of research participants. In Scotland, most research studies involving people can only commence if the study has received both NHS Research & Development (R&D) permission, and a favourable opinion from a Research Ethics Committee (REC). Participant safety and confidentiality is of the utmost importance; and participants can request that all their information, data and samples from the trial or study be destroyed. The National Institute for Health and Care Research (NIHR) provides useful information and tackles some common misconceptions about health and social care research on their *Be Part of Research* website designed to promote and explain research to the public[74].

After a research study has undergone the necessary review, they can begin to recruit participants. Consent is an essential component of the recruitment process – by providing the necessary and relevant information in a comprehensible manner, individuals can make an informed decision about whether participating in a research study is suitable for them. Participants can change their mind and withdraw their consent and further participation in a trial at any point without giving a reason. Refusing to take part in research, or withdrawing consent at any time, will not impact the standard of care received.

[73] NHS Health Research Authority. UK Policy Framework for Health and Social Care Research.
[74] Be Part of Research.

Defining incapacity

For a number of reasons, not all individuals possess the capacity to make an informed decision regarding their own participation in a trial. Assessing the capacity of adults is not a simple process. The law in Scotland generally presumes that adults are capable of making personal decisions for themselves and managing their own affairs. Having a diagnosis of dementia, for example, does not necessarily mean that a person is incapable of making their own decisions. When assessing capacity, evidence of the individual's ability to understand any potential risks, and a consistency in this understanding, is considered. Section 1(6) of the AWI Act defines a person over 16 as 'incapable' if they are incapable of:

- acting; or
- making decisions; or
- communicating decisions; or
- understanding decisions; or
- retaining the memory of decisions,
- by reason of mental disorder or an inability to communicate due to a physical disability that cannot be improved by an external aid.

Furthermore, incapacity is not always permanent, and the nature of an individual's incapacity can be dependent on the condition or illness they are experiencing. The reasons for incapacity can be incredibly varied, and may include conditions like dementia, severe trauma caused by accidents that render individuals unconscious, learning difficulties, mental states such as delirium, amongst many others. Incapacity can also be temporarily caused by a particular treatment regime received by an individual (e.g. patients being placed in medically induced comas).

Research governance in the NHS in Scotland and the wider UK

As discussed above, section 51 of the AWI Act provides governance for how adults incapable of giving consent can participate in medical, surgical, dental, nursing or psychological research, subject to certain safeguards and exceptions. In Scotland, over 1,500 clinical research studies encompassing a range of conditions and specialities involving over 30,000 patients take place each year[75]. Research in Scotland is robustly regulated and there is no intention to change that. Further information on research governance in Scotland can be found on the NHS Research Scotland website[76]. Other guidance outlining principles of good practice in the area of health and social care research can be found in the UK Policy Framework for Health and Social Care Research[77].

Research in the NHS can be broadly grouped into two categories. Clinical Trials of an Investigational Medicinal Product (CTIMP) involve trialling a new drug, or trialling an existing drug for a purpose distinct from the one for which it was originally

[75] NHS Research Scotland. Take Part in Current Research (NHS Research Scotland).
[76] NHS Research Scotland. Research Governance (NHS Research Scotland).
[77] NHS Health Research Authority. UK Policy Framework for Health and Social Care Research.

approved. Studies that do not involve testing new drugs are categorised as non-CTIMP studies. Each of these two types of studies are governed in different ways across the UK.

It must be noted that social care research is not necessarily always conducted in an NHS setting. When it is not, it is thus not necessarily governed by the same set of rules and regulations outlined below. However, when a social care research study involves adults with incapacity in Scotland, it is typically reviewed by a specific NHS Research Ethics Committee (see **Research Ethics Committees (RECs)** below).

Clinical trials of investigational medicinal products (CTIMPs)

Existing regulations governing CTIMP studies originally came into UK law via EU Directive[78], in the form of The Medicines for Human Use (Clinical Trials) Regulations 2004[79] which, together with its amendments, are referred to as the Clinical Trial Regulations. The Medicines for Human Use (Clinical Trials) Regulations 2004 are currently under review and work is being performed to amend and update this legislation. Approval processes governing CTIMP research studies may therefore be subject to any amendments to existing legislation that may be implemented in the future. This legislation is a reserved matter under the UK Government. A general explanation of matters devolved to Scotland or reserved to the UK can be found on the Scottish Parliament's website[80].

In addition to Research Ethics Committee (REC) review and NHS R&D approval discussed above, CTIMP studies require an extra step of authorisation before they can commence. In practice, this involves applying to the Medicines and Healthcare products Regulatory Agency (MHRA) for a clinical trial authorisation.

When a researcher wishes to obtain permission for a potential participant to enter a study when they lack capacity and there is adequate time to consult, the UK Clinical Trials Regulations (henceforth known as 'the Clinical Trials Regulations') allow for a personal or professional legal representative to consent on behalf of the participant in order that they may be given the opportunity to participate in the trial[81].

The Clinical Trials Regulations inserted provisions into Section 51 of the Act[82] to allow for an incapacitated adult to enter a study in instances where there is inadequate time to consult the individual's relevant representatives. This is permissible by means of an emergency provision or waiver of consent if:

- It has not been practicable to contact the adult's guardian, welfare attorney or the adult's nearest relative before the decision to enter the adult as a subject of the clinical trial is made and consent has been obtained by the individual's primarily responsible doctor or somebody nominated by the relevant healthcare provider,

[78] Note: on 31 January 2022, the EU Directive mentioned in the text (the Clinical Trials Directive (2001/20/EC)) was replaced by the Clinical Trials Regulation (EU No 536/2014) in the EU.
[79] The Medicines for Human Use (Clinical Trials) Regulations 2004, No. 1031.
[80] Scottish Parliament. About the Scottish Parliament: Devolved and Reserved Powers (Scottish Parliament)
[81] The Medicines for Human Use (Clinical Trials) Regulations 2004, No. 1031, sch 1.
[82] The Adults with Incapacity (Scotland) Act 2000, s. 51(3A).

- Where treatment is being given, or is about to be given to the adult, the involvement of the individual in the study is a matter of urgency, and it is not reasonably practicable to obtain consent from the adult's guardian, welfare attorney or nearest relative or from the individual's primarily responsible doctor or somebody nominated by the relevant healthcare provider, and the action to be taken is in accordance with a procedure approved by Scotland A REC or any other Ethics Committee established or recognised under Part 2 of the Clinical Trials regulations or the Gene Therapy Advisory Committee.

However, it should be noted that aside from the provisions inserted into Section 51 of the Act, the overall processes that apply to CTIMPs (including further rules that would apply to CTIMPs on incapacitated adults or otherwise) are governed throughout the UK by these Clinical Trials Regulations, and not the AWI Act. Therefore, CTIMP studies lie outside the scope of the proposals outlined in this consultation.

Non-CTIMP studies

Whilst the proposals found in this consultation are not relevant to studies involving investigational medicinal products (CTIMPs), governance of all other research in NHS Scotland (referred to as non-CTIMPs) is devolved to Scotland and, in the case of research including incapacitated adults, is governed through the AWI Act and associated Regulations[83]. In practice, when compared to the rest of the UK, this means adults with incapacity in Scotland involved in research may experience a different approach depending on the nature of the study.

In a non-CTIMP study in Scotland under the Act, when a researcher wishes to obtain permission for an incapacitated individual to enter a study, the individual's guardian, welfare attorney or nearest relative can provide legal consent[84]. Here, there are also additional conditions that must be met[85], including:

- Research of a similar nature must not be able to be carried out on an adult who has capacity.
- The purpose of the research must be to obtain knowledge on the causes, diagnosis, treatment or care of the adult's incapacity, or to obtain knowledge on the effect of treatment or care given during the adult's incapacity which relates to that incapacity.

Under the analogous legislation in England and Wales (the Mental Capacity Act 2005) and Northern Ireland (the Mental Capacity Act (Northern Ireland) 2016), in a non-CTIMP study, when a researcher wishes to obtain permission for a potential participant who lacks capacity to enter a study, a personal consultee (similar to a personal legal representative) or nominated/professional consultee can provide permission[86,87]. In Scotland, in a non-CTIMP study, there is no provision for a

[83] The Adults with Incapacity (Ethics Committee) (Scotland) Regulations 2002.
[84] The Adults with Incapacity (Scotland) Act 2000, s. 51(3)(f).
[85] The Adults with Incapacity (Scotland) Act 2000, s. 51(1) and s. 51(2).
[86] The Mental Capacity Act 2005, s. 32(2) and s. 32(3).
[87] The Mental Capacity Act (Northern Ireland) 2016, s. 135(2) and s. 135(3)

nominated/professional consultee to provide consent for a potential participant to be involved in a research study in cases where the prospective participant lacks capacity.

If there is not adequate time to consult, in England, Wales and Northern Ireland, there is also the possibility of obtaining permission for a potential participant to enter a study through an emergency provision, or waiver of consent. This is also not possible in Scotland for non-CTIMP research studies.

Research Ethics Committees (RECs)

Most research proposals undertaken within the NHS or involving NHS patients – whether CTIMP or non-CTIMP – are reviewed by a Research Ethics Committee (REC)[88]. Operating as part of a UK-wide Research Ethics Service, there are 12 RECs in Scotland which analyse hundreds of applications each year (over 380 between the beginning of April 2019 and the end of March 2020 alone)[89]. Each REC is comprised of volunteer lay and expert members who all possess a diverse range of knowledge and expertise. RECs also act independently of researchers, funders and sponsors, allowing them to review research applications objectively and to ensure the wellbeing, safety and rights of participants are at the centre of the review process. However, only one REC (Scotland A REC – SAREC), established by regulation 2 of the Adults with Incapacity (Ethics Committee) (Scotland) Regulations 2002 made under Section 51(6) of the Act, may review research proposals involving incapacitated adults in Scotland. Further information about the activities of the RECs and the wider Scottish Research Ethics Service can be found on the NHS Research Scotland website[90].

The proposals

The following sections provide background information and context which help to illustrate the issues that each of our proposals aim to address, including the questions we would like respondents to consider. As outlined above, CTIMP research is governed by a separate UK-wide piece of legislation (The Medicines for Human Use (Clinical Trials) Regulations 2004). The questions outlined throughout the rest of this paper only propose to amend Adults with Incapacity legislation, and thus will only apply to non-CTIMP research in Scotland.

Permitting the establishment of more than one ethics committee that is able to review research proposals involving adults with incapacity

Scotland A Research Ethics Committee (SAREC)

As discussed above, Scotland A Research Ethics Committee (SAREC) is the only REC in Scotland capable of reviewing research proposals that involve adults with

[88] The Health Research Authority (HRA) has developed a useful tool that can be used to determine whether a research study conducted in the UK requires review by a Research Ethics Committee
[89] Research Ethics Service Annual Report for Scotland: April 2019 – March 2020. Scottish Research Ethics Service.
[90] NHS Research Scotland. Research Ethics Structure in Scotland (NHS Research Scotland).

incapacity. The AWI Act requires that an Ethics Committee be established by procedures, set out in the Adults with Incapacity (Ethics Committee) (Scotland) Regulations 2002. These regulations impose a strict set of criteria that ensures SAREC is comprised of members who possess a wide range of skills and expertise. At present, in order for SAREC to be quorate, there must be attendance by at least three members, which must include: the Chair, or in the Chair's absence, the Vice-Chair or an Alternate Vice-Chair; one member who meets one of the expert requirements at (a) to (h) below; and one lay member.

The membership of this Committee shall, so far as practical, include at least:

(a) one person who has experience in relation to the treatment of adults who are incapable;
(b) one medical practitioner who provides primary medical services pursuant to Part I of the National Health Service (Scotland) Act 1978;
(c) one registered nurse or registered midwife;
(d) one registered medical practitioner having experience in clinical pharmacology;
(e) one pharmacist registered in Part 1 of the register maintained under article 19 of the Pharmacy Order 2010 or a registered person as defined by Article 2(2) of the Pharmacy (Northern Ireland) Order 1976;
(f) one registered medical practitioner who holds the position of hospital consultant;
(g) one registered medical practitioner having experience in the field of public health medicine;
(h) one member who is registered as a member of a profession to which the Health Professions Order 2001 applies; and
(i) three lay members

Before approval can be given for any research under Section 51 of the AWI Act, SAREC must take into account:

(a) the objectives, design, methodology, statistical considerations and organisation of the research;
(b) the relevance of the research and the study design;
(c) the justification of predictable risks and inconveniences weighed against the anticipated benefits for the research participants and future participants;
(d) the suitability of the lead researcher;
(e) the adequacy of the written information to be given and the procedure for obtaining
consent; and
(f) the arrangements for the recruitment of research participants.

SAREC is the only committee capable of reviewing research proposals involving incapacitated adults in Scotland. Experience from operating during the COVID-19 pandemic response amplified some concerns that this may represent an operational weakness in capacity and resilience in the system. To support the COVID-19 response, the Scottish Government made Scottish Statutory Instrument SSI 2020/151 to provide for a degree of flexibility in SAREC's operations, but this was

not designed to be a long term solution, especially outside of an emergency response.

If a second committee were to be constituted, to help further improve the flexibility and resilience of the system, it could be subject to provisions that outline different procedures than are currently in place for SAREC (such as distinct membership composition requirements).

Another major consequence of the current system is that there is no right of appeal should applicants wish to challenge an unfavourable ethical opinion issued by SAREC. This is unlike all other committees throughout the UK, for which applicants have the right to appeal.

Amending the AWI Act to permit the establishment of more than one committee that is able to review AWI research proposals would boost capacity within the system, and allow for an appeals process in Scotland for AWI research studies. These changes would help to support a more efficient and resilient system, fit for purpose, as Scotland looks to grow the delivery of high quality clinical research.

Question

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?

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

Case study: Large scale research studies that make use of NHS patient data sets

Many research studies only wish to make use of NHS patient data; rather than measuring the effectiveness of new treatments or interventions on patients. In particular, it can be common for researchers to want to make use of data that is recorded from patients during routine clinical care (which could include identifiable data or non-identifiable data. Identifiable data is data through which it is possible to ascertain the identity of the individual from which the data was taken). In these cases, researchers may have to prospectively gather such data during routine care with the intention of using it for research purposes in the future; or want to make use of existing patient data sets that have already been collected. It is also common for such studies to make use of data that comes from large numbers of NHS patients.

Generally, when researchers wish to make use of NHS Scotland patient data in this manner that comes from more than one NHS Health Board they have to apply to the Public Benefit and Privacy Panel for Health and Social Care

(PBPP)[91] for approval. In addition to the Panel being satisfied that the proposed data processing by researchers will be conducted in a safe, proportionate and secure manner, that the public interest will be advanced and there is a demonstrable need for researchers to process patient data, there is an expectation that patients should be informed and provide consent when their data is processed for purposes other than standard clinical care. However, it is understood that this is not always practical or possible. In cases such as this, PBPP will require a clear explanation and justification for researchers proceeding without participant consent before approving their application. PBPP follows a number of guiding principles[92] when assessing applications, in addition to the Caldicott Principles[93] and Data Protection Principles[94].

In instances where researchers only wish to use patient data from a single NHS Board, they seek approval from that Board's Caldicott Guardian[95] instead of PBPP. A Caldicott Guardian is an individual who is responsible for ensuring that personal health and social care data is processed and stored legally, ethically, and appropriately in an organisation. The appointment of a Caldicott Guardian in each NHS organisation for safeguarding patient data in this manner was one of the central recommendations resulting from the 1997 Caldicott Report on the review of patient identifiable information[96].

Applying for Caldicott Guardian or PBPP approval is a distinct process from receiving a favourable ethical opinion from a Research Ethics Committee. For research studies involving patient data, researchers will often have to seek approval from both a Research Ethics Committee and PBPP/Caldicott Guardian. The HRA's decision tool is a useful resource that can be used by researchers who are unsure if their particular research study requires REC review.

So whilst there are specific pathways available to researchers to ensure they can safely and appropriately process routinely gathered patient data (identifiable or otherwise) for research purposes without consent in specific circumstances; for adults with incapacity to participate in research, consent being obtained from an appropriate decision-maker is always a necessary requirement under the AWI Act[97].

For any research studies that wish to make use of patient data collected from incapacitated adults, researchers would have been required to obtain consent from a relative or other surrogate decision-maker for every incapacitated participant prior to the data being processed as part of the study. This is the case both for data that is prospectively gathered during routine care in the knowledge it will also be used for research; and when data has already been collected and is held in existing NHS datasets. For large studies that involve thousands of

[91] NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP). Public Benefit and Privacy Panel for Health and Social Care.
[92] About the Public Benefit and Privacy Panel for Health and Social Care. Public Benefit and Privacy Panel for Health and Social Care
[93] The Caldicott Principles. The UK Caldicott Guardian Council.
[94] Regulation (EU) 2016/679 of the European Parliament and of the Council (UK GDPR), Article 5.
[95] NHSScotland Caldicott Guardians: Principles into Practice. Scottish Government, 2010.
[96] Report on the Review of Patient-Identifiable Information. Department of Health (The Caldicott Committee), 1997.
[97] The Adults with Incapacity (Scotland) Act 2000, s. 51(3)(f).

patients, seeking consent on behalf of participants – whether they have capacity or not – is often unfeasible.

With regards to the other UK nations, the respective pieces of legislation in these countries can allow this type of research to be carried out without needing consent from each individual participant lacking capacity.

For example, in England and Wales, if it is not feasible to obtain patient consent for the use of identifiable data about them, an application can be made to the Confidentiality Advisory Group (CAG)[98] for support under Section 251 of the NHS Act 2006 to disclose this data for use in research that is of public benefit with a medical purpose. This is because such support sets aside the common law duty of confidentiality. Approval is subject to certain conditions (notably, the implementation of safeguards and transparency). Other examples of types of research where no consent is required to lawfully involve a person in a research study in England and Wales (regardless of whether they possess capacity or not) can be found on page 205 of the Mental Capacity Act 2005 Code of Practice[99]. Such research is defined as 'non-intrusive research'. Other examples of 'non-intrusive research' are highlighted on the HRA's website[100].

The Mental Capacity Act 2005 (which applies in England and Wales, not Scotland) only provides governance for 'intrusive research'[101] – research in which it would be unlawful to carry out on a person with capacity without their consent. Therefore, any provision outlined in the Mental Capacity Act (such as the research being connected with an impairing condition affecting the person lacking capacity, or the researchers having to locate an appropriate person to consult with about the suitability of an individual with incapacity to take part in a given study) do not apply to non-intrusive research practices, such as processing identifiable patient data with section 251 support.

Thus, in England and Wales, researchers do not have to identify a consultee to discuss participation for adults with incapacity for non-intrusive research. In cases where researchers want to make use of identifiable patient data in this manner, they must apply to the HRA's Confidentiality Advisory Group (CAG). However, before approaching CAG, researchers must explore all other practical alternatives and clearly demonstrate that seeking consultee advice is not practical in their particular circumstances. The CAG will review the research application and provide expert advice to the HRA about whether or not it should be approved to allow researchers access to such data without patient consent. More information about the CAG can be found on the HRA's website[102].

Currently in Scotland, regardless of Caldicott Guardian or PBPP approval, Scotland A REC would not be able to review and approve any research study involving data taken from incapacitated adults without consent being sought from a guardian, welfare attorney or nearest relative; even if it is possible for research

[98] Confidentiality Advisory Group. NHS Health Research Authority.
[99] Mental Capacity Act 2005: Code of Practice. Department of Constitutional Affairs, 2007.
[100] NHS Health Research Authority. The Mental Capacity Act 2021.
[101] The Mental Capacity Act 2005, s. 30.
[102] Confidentiality Advisory Group. NHS Health Research Authority.

studies involving data taken from adults with capacity to be approved and proceed without consent under certain circumstances.

The above case study highlights that it can be very difficult to conduct large scale studies using data taken from adults with incapacity in Scotland; risking their exclusion in instances where it is unfeasible to obtain consent from the individual's surrogate decision-maker. Ultimately, this can lead to situations where data collected from an adult with capacity can be included in a research study without their consent, but data collected from an adult with incapacity could not.

Practically speaking, the research studies discussed in this section and impacted by the proposals outlined later in this section (questions 92 & 93) would **not** include interventional studies. Interventional studies are research studies in which a new or changed treatment or care is tested on participants. These proposals would only affect non-interventional studies; primarily non-interventional studies that involve patient data taken from adults with incapacity.

To clarify, as mentioned above, so long as the appropriate approval is in place (information governance approval through Caldicott Guardian/PBPP and, where appropriate, REC favourable opinion), it is possible for adults with capacity to be included as participants in the following types of non-interventional research without giving consent; but not adults with incapacity:

- Research studies that involve prospectively gathering NHS patient data (identifiable or otherwise) during routine care with the intention of subsequently using the data for research purposes.
- Research studies that wish to make use of existing NHS patient data sets (identifiable or otherwise).

This imbalance in approach risks the integrity of research outcomes and healthcare benefits for adults with incapacity if they continue to be excluded from such studies.

In terms of participating in research, we are seeking views on the principle of allowing adults with incapacity to be included as participants in research studies without consent, in instances where adults with capacity are already able to be included as participants without consent.

Question

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?

This general principle would avoid situations in research studies that involve, for example, data taken from adults with incapacity being unintentionally excluded due to it being incredibly impractical to seek consent from an appropriate person for each

incapacitated participant; whilst unconsented data from adults with capacity can be used in the study if the appropriate approvals are in place.

One example of how this general principle could be implemented in a practical way would be to provide Scotland A REC (or any other ethics committee constituted under Regulations made by the Scottish Ministers in the future) with the ability to determine that, just like the current practice for studies involving participants with capacity, there will be certain special circumstances in which researchers would not be required to obtain consent to involve adults with incapacity in research studies.

If this proposal were to be implemented, the relevant ethics committee would only rule that a study involving adults with incapacity could proceed without obtaining consent if they would be content that an ethics committee would also provide a favourable opinion to such a study proposing to involve adults with capacity as participants without consent.

As discussed before, this in practice would **not** apply to interventional studies, and, just like the current situation where RECs review such applications involving participants with capacity, Scotland A REC (or any other ethics committee constituted under Regulations made by the Scottish Ministers in the future) would need to be satisfied that the wellbeing and rights of the participants are protected and that researchers have a sound justification for proceeding without consent. In addition to REC review, an extra safeguard is also in place for research studies involving patient data in Scotland. As mentioned above, at present such studies involving participants with capacity generally require separate information governance oversight and approval from a Caldicott Guardian (when patient data comes from a single NHS Board) or PBPP (when access to patient data is requested from more than one NHS Board); and it is common practice currently for RECs to confirm that this approval is in place before a favourable opinion is provided and the research study can commence.

If implemented, the central aim of this proposal would be to allow incapacitated participants to follow the same research approval pathways that are already in place for participants with capacity.

As with the other questions posed throughout this consultation, this proposal is made with the principle of equality in mind, to ensure adults with incapacity are not disadvantaged when it comes to accessing research.

Question

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?

Pathways for emergency waivers of consent

Case study: Recovering from trauma

Patients attending the emergency department with trauma, for example after a car accident, may not have capacity due to the injuries they received rendering them unconscious. These patients are seriously ill and sometimes may not survive. It is important that new treatments are tested to see whether they can improve survival.

In 2017, the E-FIT1 trial[103] tested one such treatment. Fibrinogen is a component of blood that performs a key role in the clotting process following injury, and its levels are known to fall in trauma patients. The trial studied whether replacing fibrinogen would reduce bleeding and improve survival.

In Scotland, trauma patients were able to take part in this study because the fibrinogen used was classified as a drug (or Investigational Medicinal Product; IMP). Thus, even though the study involved adults with incapacity, it was governed by CTIMP regulations – the UK Clinical Trials Regulations which inserted relevant provision into the AWI Act. In an emergency situation such as an individual experiencing a trauma, section 51(3A) of the AWI Act offers the provision for waivers of consent to be applied in certain circumstances. This allows for patients with incapacity to be enrolled in a study and receive research treatment in urgent situations without firstly seeking consent from an appropriate third person (guardian, welfare attorney or nearest relative) if it is not practicable to do so.

These waivers of consent are only applied in very specific circumstances, predominantly in emergency situations where treatment has to be applied to the patient urgently and there is not sufficient time to firstly locate and consult an appropriate representative of the patient who has lost capacity. Under section 51(3A) of the AWI Act this waiver of consent to allow a patient to receive immediate research treatment only applies if an ethics committee has approved the study and a professional representative, in this case the doctor leading the trauma team, agrees that the patient should be entered into the study. Consent can then be sought from the patient at a later time, when they regain consciousness and capacity, where they can decide if they wish to continue participating in the research treatment (in this instance, receiving fibrinogen). If the participant does not regain capacity, consent can be sought from the appropriate representative (e.g. nearest relative) when practicable.

In 2017, a similar trial called CRYOSTAT-2[104] opened in England. This tested whether a product called cryoprecipitate could reduce mortality in trauma patients, in a similar manner to the fibrinogen used in the E-FIT 1 trials. Cryoprecipitate is a frozen donated blood product containing fibrinogen.

[103] Curry N, et al. Early fibrinogen concentrate therapy for major haemorrhage in trauma (E-FIT 1): results from a UK multi-centre, randomised, double blind, placebo-controlled pilot trail. Crit Care., 2018; 22:164.
[104] Marsden M, et al. Coagulopathy, cryoprecipitate and CRYOSTAT-2: realising the potential of a nationwide trauma system for a national clinical trial. Br. J. Anaesth, 2019; 122(2), 164-169.

Cryoprecipitate is natural and is licensed as a blood product, as opposed to manufactured like the fibrinogen in the E-FIT 1 trials. Because of this, cryoprecipitate is not classified as a drug. Treating with cryoprecipitate is therefore not governed by the Clinical Trials Regulations; meaning that, when the study involves treating adults with incapacity, it is governed by the AWI Act in Scotland, the Mental Capacity Act 2005 in England and Wales, and the Mental Capacity Act (Northern Ireland) 2016 in Northern Ireland.

Whilst, similarly to the Clinical Trials Regulations, both Mental Capacity Acts mentioned above have provision for emergency waivers of consent[105,106] in situations like the CRYOSTAT-2 trial; the AWI Act does not. Under the Act, seeking consent for adults with incapacity to participate in non-CTIMP research is a necessity in Scotland, even in emergency situations like those mentioned above where it is not always possible to find and seek consent from an incapacitated adult's appropriate representative in a relevant timeframe for the research study. Therefore, studies such as CRYOSTAT-2 would be unlawful in Scotland. As such, Scottish patients were not involved in the study, and were not offered this potentially life-saving treatment.

There are a number of other studies in the area of emergency medicine that are currently incompatible with the terms of the AWI Act in Scotland as a result of the AWI Act lacking such provision, including but not limited to:

- The Spinal Immobilisation Study (SIS)[107] which aims to assess neck immobilisation in patients who are suspected of a spinal injury in the pre-hospital and emergency setting.

- The SWIFT trial (Study of Whole blood In Frontline Trauma)[108] in England and Wales. Akin to the cryoprecipitate treatment mentioned above, whole blood is also natural and is licensed as a blood product and not a drug. It is therefore not governed by section 51(3A) of the AWI Act that relates to CTIMP studies, and patients with incapacity in Scotland would have to be excluded from the study as it would be governed by other subsections of section 51 of the Act.

- The CoMiT-ED Trial (Conservative Management in Traumatic Pneumothoraces in the Emergency Department)[109] aiming to find out whether a collapsed lung (pneumothorax) due to injury (trauma) can be safely and effectively treated without immediately inserting a tube into the chest.

[105] The Mental Capacity Act 2005, s. 32(8), 32(9) and 32(10)
[106] The Mental Capacity Act (Northern Ireland) 2016, s. 136
[107] National Institute for Health and Care Research. Spinal Immobilisation Study (National Institute for Health and Care Research)
[108] NHS Blood and Transplant. SWIFT: Study of Whole blood In Frontline Trauma.
[109] National Institute for Health and Care Research. Conservative Management in Traumatic Pneumothoraces in the Emergency Department

- The AIRWAYS 3 Trial[110], which aims to test a new method of treatment for patients that experience in-hospital cardiac arrest. The study will compare whether inserting a new type of airway device in the throat to assist and improve breathing is more effective than the current method of tracheal intubation (placing a breathing tube in the windpipe).

As mentioned above, the severe nature of the conditions experienced by patients eligible for the aforementioned studies means that delivering treatment is a matter of urgency, and that seeking consent from surrogate decision-makers is often not practicable. The current AWI Act offers no provision for emergency waivers of consent to be applied for this type of non-CTIMP research, preventing patients with incapacity from being enrolled in suitable research studies and receiving treatment, before then seeking consent from the appropriate persons at a later time. As a result, in Scotland, trauma and emergency research is only able to focus on better providing the care we know helps patients and, not on establishing new and improved treatments via research for patients suffering from these conditions. The following two proposals put forward two pathways that would permit waivers of consent to be applied in special circumstances.

Amending the AWI Act to allow emergency waivers of consent to be applied in specific situations would offer adults lacking capacity additional opportunities to participate in relevant non-CTIMP research studies. This would be where it is necessary to provide the research intervention and/or practice as a matter of urgency and it is not practicable to firstly obtain consent from an appropriate representative (guardian, welfare attorney, or nearest relative of the individual).

Firstly, we ask if the AWI Act should be amended to permit researchers to consult with a medical practitioner not associated with the research study regarding the suitability of a particular adult with incapacity to participate in the study. If the researcher and medical practitioner are in agreement, the individual can participate in the study. The appropriate representative of the individual (or the individual themself if they regain capacity during the research project) can then be consulted at the nearest practicable time, and decide whether the individual should continue participating in the research study.

Question

94. Should the AWI 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?

[110] National Institute for Health and Care Research. Randomised trial of the clinical and cost effectiveness of a supraglottic airway device versus tracheal intubation during in-hospital cardiac arrest

In certain cases it may not even be practical, or there may not even be sufficient time, for researchers to consult with a registered medical practitioner in this manner. In such urgent cases, the AWI Act could be amended to permit researchers to enrol adults with incapacity in studies without the consent of their guardian, welfare attorney or nearest relative; or consulting a registered medical practitioner as outlined in the proposal above. This would only be possible in situations where the researchers act in a manner that adheres to protocols outlined in advance in their research application and which have undergone ethical review by Scotland A REC (or any other ethics committee constituted by Regulations made by the Scottish Ministers in the future).

Amending the AWI Act in this manner would provide another pathway for emergency waivers of consent to be provided for adults with incapacity in addition to the proposal described above (Q94).

If this were to be adopted in Adults with Incapacity legislation, researchers could enrol incapacitated patients in research studies without the consent of an appropriate representative of the individual. To reiterate, this would only apply in very specific emergency situations, namely:

- It is necessary to take action for the purposes of the specific research study in question as a matter of urgency, and
- It is not practical or feasible to obtain consent from the individual's usual appropriate decision-maker, and
- It is not practical or feasible to obtain consent from a registered medical practitioner (note: this would only apply if the above proposal (Q94) were to be implemented)
- The researchers act in accordance with procedures they outlined in their research application, which has been approved by Scotland A REC (or any other ethics committee constituted by Regulations made by the Scottish Ministers in the future)

If an incapacitated adult is enrolled in a study in this manner, at the nearest practicable time, their appropriate decision-maker (e.g. guardian, welfare attorney or nearest relative) would be approached and asked whether the individual should continue to participate in the study.

Question

95. Should the AWI 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)?

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

In its current form, the AWI Act only permits a guardian, welfare attorney or nearest relative to provide consent for adults with incapacity to participate in non-CTIMP research[111]. In circumstances where these surrogate decision-makers cannot be reached, there is no pathway in the AWI Act that allows adults with incapacity to participate in non-CTIMP studies.

Outside of the concept of waivers of consent applied in urgent and emergency situations as discussed in the previous section, another option that would increase the number of routes available to adults with incapacity to participate in research could be to expand the list of approved persons who can provide consent on their behalf. An example of this could be to amend the AWI Act to include a provision for researchers to nominate an individual to consult with about the suitability of involving a particular adult with incapacity in a research project. This nominated person would be somebody involved in the professional care of that individual (e.g. their GP, nurse or social care worker), provided they are not associated with the research project in question. However, as long as the nominated person has a professional duty of care for the incapable adult in question, there would be no requirement for the nominated person to belong to a particular profession.

The exact nature of how nominated persons are selected would be specified in each research proposal that would be submitted to Scotland A REC (or any other ethics committee constituted by regulations made by the Scottish Ministers) for review and approval. If both the researcher and nominated person agree that it would be appropriate for the individual to participate in a particular research project, they can be enrolled in the study. However, if at any time the nominated person believes it is no longer suitable for the individual to participate, they will be withdrawn from the study.

Unlike the previous proposals (Q94 and Q95), it is important to note that such a provision could be used even outside of urgent and emergency situations.

Implementing this change to the AWI Act would expand the list of individuals permitted to provide consent for adults with incapacity, providing these individuals with more pathways to participate in research where appropriate. Whilst such a provision could be used even outside of emergency situations, researchers would only be able to nominate a professional consultee (a person with a professional duty of care for an adult with incapacity, e.g. the individual's carer, nurse, social care worker or GP) to provide consent for the incapacitated adult to participate research study if the researchers have already made reasonable steps to try and contact a guardian, welfare attorney, or nearest relative of the individual without success, and the nominated person is not associated with the research study in question.

[111] Adults with Incapacity (Scotland) Act 2000, s. 51(3f).

Question

96. Should the AWI 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?

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

As of now, the AWI Act only permits individuals with incapacity to participate in research that cannot be carried out on an adult who has capacity and that the research in question hopes to obtain knowledge about 'the causes, diagnosis, treatment or care of the adult's incapacity; or the effect of any treatment or care given during his incapacity to the adult which relates to that incapacity'[112]. In other words, there is no provision in the AWI Act that permits adults with incapacity to participate in research relating to any other medical conditions that individual may experience that are not linked to the individual's incapacity; or indeed research of any other nature.

Case study: Multimorbidity and an aging population

As people age, their risk of developing certain conditions increases. For example, bearing in mind that National Records of Scotland figures for 2019 estimate that 19% of Scotland's population is aged 65 and above[113], the below conditions appear to be greatly overrepresented in older people:

- **Dementia**: estimates suggest 96.7% of individuals diagnosed with dementia in 2020 in Scotland were aged 65 and above[114].
- **Type 2 Diabetes**: of the 278,143 individuals with Type 2 Diabetes in Scotland recorded in the 2020 Scottish Diabetes Survey, 57.7% were aged 65 and above[115].
- **Cancer**: 34,133 individuals were diagnosed with cancer in Scotland in 2019, with 76% of such diagnoses occurring in individuals aged 60 and above[116].

Individuals can also experience multiple conditions, such as those outlined above, simultaneously. Living with more than one chronic condition at the same time is known as multimorbidity. Despite affecting a broad range of individuals across many age groups, multimorbidity is more prevalent in older people[117]. With the age profile of Scotland's population predicted to increase in the coming years – with the proportion of the population above the pensionable age

[112] Adults with Incapacity (Scotland) Act 2000, s. 51(2)
[113] Scotland's Population: The Registrar General's Annual Review of Demographic Trends 2019. National Records of Scotland, 2020.
[114] Estimated and Projected Diagnosis Rates for Dementia in Scotland: 2014-2020. Scottish Government, 2016.
[115] Scottish Diabetes Survey 2020. NHS Scotland, Scottish Diabetes Data Group, 2020
[116] Cancer Incidence and Prevalence in Scotland (to December 2019). Public Health Scotland, 2021. Figures include all forms of cancer except non-melanoma skin cancer
[117] Multimorbidity: a priority for global health research. Academy of Medical Sciences, 2018.

estimated to increase to 22.9% by 2043[118] – rates of multimorbidity are also likely to rise in Scotland.

This is not a phenomenon restricted to Scotland. A high prevalence of multimorbidity in older populations is observed across many regions of the world[119]. All of this data points towards a higher likelihood of adults with incapacity experiencing multimorbidity as they age, and living with conditions that do not necessarily relate to their incapacity. The current form of the AWI Act precludes incapacitated individuals with multimorbidity from participating in studies for conditions they experience that do not relate to their incapacity. One way in which this issue could be resolved would be to amend the AWI Act in a manner that does not restrict the type of research studies incapacitated individuals can participate in to those that investigate conditions related to their incapacity. This, however, could be achieved in one of several ways. For example, the AWI Act could be amended to allow adults with incapacity to participate in:

- Research into conditions arising as a consequence of the adult's incapacity, or;
- Research into any condition – related to their incapacity or not – that the adult experiences, or;
- Any type of research.

Each of these possibilities are discussed below.

It can be the case that adults with incapacitating conditions are predisposed to suffering from other conditions. For example, the symptoms associated with dementia can place people with such a condition at a higher risk of suffering a fall[120], which can consequently lead to serious injuries such as hip fractures in some instances. A strict reading of the current Act may preclude dementia patients with incapacity from participating in hip fracture studies, since hip fractures do not necessarily directly relate to the individual's incapacity in the manner that is stipulated in the Act. One possibility would be to amend the AWI Act to allow adults with incapacity to participate in research projects that also involve any conditions that arise as a consequence of the adult's incapacity:

Question

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

Unlike the above example that highlighted potential injuries or conditions that may arise as a consequence of an individual's incapacity, there are also cases where some individuals may experience a medical condition that is completely unrelated to

[118] Projected Population of Scotland – 2018-based. National Records of Scotland, 2019.
[119] Multimorbidity: a priority for global health research. Academy of Medical Sciences, 2018.
[120] Falls and dementia. NHS Inform, 2022.

their incapacity. For example, some people may experience chronic conditions or illnesses before then developing a condition that may cause them to lose capacity. In these instances, under the current Act, such individuals may not be permitted to participate in research that investigates the original chronic condition they started to experience before they developed a separate condition that resulted in their loss of capacity. One proposal to resolve this would be to amend the AWI Act to allow adults with incapacity to participate in research studies that investigate any condition they may experience – regardless of whether it relates to their incapacity or not.

Question

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

Research should lead to novel care and treatment regimens that are widely applicable across the population. Developing processes where a wider range of people, including adults with incapacity, can participate in research is likely to make the outcomes of such studies more robust and applicable to the population as a whole. In addition, by excluding adults with incapacity from participating in certain types of research, we may risk research outcomes not catering to the needs of these individuals. For example, whilst people may not currently experience a particular condition, they could be at risk of developing that condition in the future as a result of their genetic predisposition, their age, or other pre-existing conditions they experience.

In situations such as this, it is important to understand how people at risk of developing a particular condition can take steps to reduce their chances of developing that condition. By allowing adults with incapacity to participate in research studies that may explore conditions that they do not personally experience, this opens up the possibility for adults with incapacity to participate in preventative research studies for conditions they could be at an elevated risk of developing. This in turn could improve our understanding of the progression of these conditions and help provide insights into the steps that adults with incapacity can take to help reduce their chances of developing conditions in the future.

To summarise, a further possibility would be to amend the AWI Act to allow adults with incapacity to participate in any type of research; provided that the same stringent safeguards and checks are applied to ensure the wellbeing and rights of these individuals:

Question

Should the AWI 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?

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-83601-462-1 (web only)

Published by The Scottish Government, July 2024

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1440826 (07/24)